

EUROPEAN DOCTORAL THESIS

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**EXPRESSED EMOTION AMONG CARERS OF PATIENTS  
WITH AN EATING DISORDER: ITS ASSESSMENT AND  
PROGNOSTIC SIGNIFICANCE FOR THE IMPROVEMENT OF  
THE CAREGIVING EXPERIENCE**

AUTHOR:

DIMITRA ANASTASIADOU

DIRECTOR:

ANA R. SEPÚLVEDA

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FACULTAD DE PSICOLOGÍA

DEPARTAMENTO DE PSICOLOGIA BIOLOGICA Y DE LA SALUD  
PROGRAMA DE DOCTORADO EN PSICOLOGIA CLINICA Y DE LA  
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**Expressed Emotion among carers of patients with an eating disorder:  
Its assessment and prognostic significance for the improvement of the  
caregiving experience**

Dimitra Anastasiadou



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## **GENERAL INTRODUCTION**

The experience of caring for someone suffering from an eating disorder is stressful and demanding. Families often find themselves stuck in unhelpful patterns of response to the illness which may serve as maintenance factors for the disorder and lead to a more burdensome caregiving experience. Efforts to achieve a deeper understanding of why eating disorder symptoms are maintained have focused mainly on the role of the emotional climate at home and have identified expressed emotion as a core factor associated with the outcome of the illness. In particular, studies have shown that high levels of expressed emotion are associated with poor illness outcome and also with high levels of distress among carers. Family-based interventions aimed to reduce levels of expressed emotion have proved to be beneficial for both carers and patients.

There is a lack of knowledge related to the measurement of expressed emotion among Spanish carers. More specifically, at the present moment there are not any self-report instruments assessing relatives' perceptions of expressed emotion that are translated and validated in the Spanish population.

This thesis intends to further advance the understanding of expressed emotion as a key maintenance mechanism in eating disorders as well as assess its reliable and valid measurement in Spain. Thus, this thesis will empirically validate, in a Spanish population, two self-report instruments assessing carers' perceptions of expressed emotion, following international standards regarding the translation and adaptation of tests. In addition, it will fill some gaps in the understanding of family caregiving in eating disorders. To do so, differences between mothers' and fathers' appraisals of expressed emotion will be explored and the role of illness-related behaviors and symptoms as predictors of psychological distress among carers will be also examined.

The overall structure of the introduction section of this thesis takes the form of four chapters. The first chapter provides a short introduction to eating disorders, briefly touching on their etiology, prevalence, adverse manifestations and prognosis. The second chapter talks about family caregiving in eating disorders. The third chapter focuses on the role of family in the development and maintenance of eating disorders. Finally, the fourth chapter points out the role of expressed emotion as a key maintenance factor in eating disorders by analyzing the findings of recent studies and by



reviewing the measures used to assess the construct among families. The aims of the thesis and the hypothesis are presented later in this section.

This thesis is presented as a compendium of three articles published in JCR indexed journals during the three academic years of the PhD studies of the candidate (2012-2014). **Study 1** titled *“The Spanish Validation of Level of Expressed Emotion Scale for Relatives of People with Eating Disorders”* examines the psychometric properties of the Spanish version of the Level of Expressed Emotion scale (LEE-S) among carers of patients with an eating disorder. **Study 2** titled *“Spanish validation of the Family Questionnaire (FQ) in families of patients with an eating disorder: Differences in expressed emotion by gender”* evaluates the psychometric properties of another self-report instrument assessing carers’ appraisals of expressed emotion in a Spanish population (FQ-S) and further examines the differences between mothers’ and fathers’ emotional response to an eating disorder. **Study 3** titled *“Impact of caregiving experience on mental health among caregivers: a comparison of eating disorder patients with purging and non-purging behaviors”* explores the differences in mental health among primary carers of patients with purging and non-purging behaviors and determines predictors of psychopathological distress among them.

The samples of carers of the present thesis were collected in three public hospitals in Spain and one Spanish association for carers. Our samples are considered large and representative. The Hospital Infantil Niño Jesús is the referral hospital for the whole of Spain for child and adolescent cases of eating disorders, receiving approximately 180 new patients with an eating disorder annually. The Hospital Infanta Cristina de Badajoz has an adult eating disorder unit which is one of the two referral eating disorder units in Extremadura, together with the unit of Cáceres. The Hospital Universitario Marques de Valdecilla is the referral hospital for child/adolescent and adult cases of eating disorders in Cantabria, having received approximately 312 patients in the last two years. The Spanish Eating Disorders Carers Association (ADANER) is a referral non-profit association for the defense of EDs in Spain with a wide range of activities organized weekly for patients and carers. The carers/members of the Madrid chapter of ADANER, which organizes a number of activities in collaboration with the Hospital Infantil Niño Jesús, were selected for Study 1 and Study 3. A detailed description of the characteristics of each sample of carers, the measures used in each study as well as the procedures and statistical analyses followed can be found in the correspondent papers.

### ***Introduction section***

The thesis concludes with a general discussion of the main findings. Clinical implications of the findings, limitations and directions for future research are also outlined. Finally, the main contributions of this thesis are presented in the conclusion section at the end of the thesis.

## **CHAPTER 1. EATING DISORDERS**

### **1.1. Introduction to Chapter**

This chapter provides a short introduction to Eating Disorders (EDs), briefly touching on their etiology, prevalence, adverse manifestations and prognosis. Later, the diagnostic categories for EDs according to the DSM-IV and its more recent version, the DSM-V, are described, before moving towards a dimensional perspective on EDs according to which significant behaviors and clinical manifestations of the illness merit special attention in future treatment settings.

### **1.2. Eating Disorders**

EDs are biologically based, serious mental illnesses (SMIs) that warrant the same level and breadth of health care coverage as other conditions currently categorized in this way (e.g., schizophrenia, bipolar disorder, depression, obsessive-compulsive disorder) (Klump, Bulik, Kaye, Treasure, & Tyson, 2009).

EDs are essentially “cognitive disorders” that share a distinctive “core psychopathology” of over-evaluation of shape and weight and their control. This core psychopathology has a major impact on the eating habits of the individual suffering from the illness. Thus, it results in sustained and extreme attempts to limit caloric intake by means of food restriction, over-exercising or the usage of diuretics and laxatives. All these behaviors cause, in turn, an important deterioration of the individual's physical and mental health, often irreversible, persistent and life-threatening. According to the most recent version of the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V; American Psychiatric Association, 2013), EDs are divided into four main categories: Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge Eating Disorder (BED) and Eating Disorder Not Otherwise Specified (EDNOS). The first three diagnoses in which EDs are divided are commonly used in clinical practice and research. However, EDNOS categorization is somewhat troublesome and often impedes clinical communication due to its heterogeneity and the inclusion of residual ED cases.

EDs present a multifactorial etiology, including a combination of genetic, biological and personality vulnerabilities which interact with environmental factors to further increase the risk of their development (Klump et al., 2009; Toro, Guerrero, Sentis, Castro, & Puertolas, 2008). The factors contributing to EDs appear to be more prevalent

within cultures where there is both a free access to food and a fashion for slimness (Grogan, 2007). In addition, among the environmental causes of EDs, the literature has shown that the family plays an essential role in the development and maintenance of the illness (Monteleone et al., 2005).

Regarding prevalence and incidence of EDs, AN is the third most common chronic disease with an adolescent onset, with a lifetime prevalence of 0.9% for women and 0.3% for men and the most frequent age of onset being around the age of 15. In turn, BN has a lifetime prevalence of 1.5% for women and 0.5% for men, with an average age of onset of 20 years. In addition, BED occurs among 3.5% of women and 2.0% of men, with an average onset of 25 years (Hudson, Hiripi, Pope, & Kessler, 2007). Finally, EDNOS is the most commonly diagnosed ED in clinical settings with a lifetime prevalence of 4.6% in adults and 4.8% in adolescents (Garner, Swanson, Crow, & Merikangas, 2012). Although EDs are increasing around the world among both women and men, the male-female ratio in EDs is still 1:10. The ED prevalence rate is estimated to be around 2.7% in adolescent girls between the ages of 13 and 17 in U. S. (Merikangas et al., 2011) and 3,4% in adolescent girls between the ages of 15 and 18 in Spain. Only 19% of this population in Spain receive treatment (Gandarillas & Sepúlveda, 2003; Gandarillas, Zorrilla, Sepúlveda, & Muñoz, 2003).

EDs present adverse effects on several life domains of the individuals suffering from them. Among them, it is important to highlight the physical, social and cognitive deterioration. In addition, it is crucial to consider the psychological impairment of patients, with most of them meeting criteria for one or more mood or anxiety disorders. Accordingly, the medical complications (due to undereating, low weight or purging behaviors) and the high levels of comorbidity with other mental disorders also deserve mentioning. All these features, together with the negative impact on family and social relationships, are cause for EDs to be viewed as a public health priority around the world, including Spain (Austin, 2011; Gandarillas et al., 2003).

The prognosis of AN is poor but highly variable: 50% of AN cases achieve complete remission. Among them, younger patients who receive a rapid and appropriate intervention present a better recovery rate. Partial remission is observed among 20 to 30% of AN patients, although between 10 to 20% of cases result in chronicity (Steinhausen, 1995). Mortality rates range from 0 to 20% and are a result of a combination of medical complications and suicide. It is worth mentioning that mortality

rates in AN are the highest of any psychiatric disorder among young females (Birmingham, Su, Hlynsky, Goldner, & Gao, 2005; Steinhausen, 2002).

In regards to patients suffering from BN, it should be pointed out that an important number of patients do not receive any kind of treatment, which therefore leads to high rates of chronicity or relapse, maintained by the “over-evaluation of thinness” belief (Fairburn, Cooper, Doll, Norman, & O’Connor, 2000). In a 6-year follow-up study, 60% of patients resulted in full remission, 30% were considered partially recovered and 10% were determined to have poor prognosis (Quadflieg & Fichter, 2003). AED affirms that “the denial or restriction of equitable and sufficient treatment necessary to avert serious health consequences and risk of death is untenable and should be vigorously protested”.

### **1.3. Categorical versus dimensional perspective on Eating Disorders**

According to the previous edition of Diagnostic and Statistical Manual of Mental Disorders, DSM-IV-TR (American Psychiatric Association, 2002), the following specific criteria are used for establishing each one of the ED diagnoses:

#### **Anorexia Nervosa**

- A. Refusal to maintain body weight at or above a minimally normal weight for age and height, for example, weight loss leading to maintenance of body weight less than 85% of that expected or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected.
- B. Intense fear of gaining weight or becoming fat, even though underweight.
- C. Disturbance in the way one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.
- D. In postmenarcheal females, amenorrhea, i.e., the absence of at least 3 consecutive menstrual cycles. A woman having periods only while on hormone medication (e.g. estrogen) still qualifies as having amenorrhea.

#### **Types**

***Restricting Type:*** During the current episode of Anorexia Nervosa, the person has not regularly engaged in binge-eating or purging behavior (self-induced vomiting or misuse of laxatives, diuretics, or enemas).

***Binge Eating/Purging Type:*** During the current episode of Anorexia Nervosa, the person has regularly engaged in binge-eating or purging behavior.

## **Bulimia Nervosa**

- A. Recurrent episodes of binge eating characterized by both: (1) Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances. (2) A sense of lack of control over eating during the episode (such as a feeling that one cannot stop eating or control what or how much one is eating).
- B. Recurrent inappropriate compensatory behavior to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, enemas, or other medications, fasting, or excessive exercise.
- C. The binge eating and inappropriate compensatory behavior both occur, on average, at least twice a week for 3 months.
- D. Self evaluation is unduly influenced by body shape and weight.
- E. The disturbance does not occur exclusively during episodes of Anorexia Nervosa.

### **Types**

**Purging Type:** During the current episode of Bulimia Nervosa, the person has regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas.

**Nonpurging Type:** During the current episode of Bulimia Nervosa, the person has used other inappropriate compensatory behavior but has not regularly engaged in self-induced vomiting or misused laxatives, diuretics, or enemas.

## **Eating Disorder Not Otherwise Specified**

This diagnosis includes disorders of eating that do not meet the criteria for the above two eating disorder diagnoses. Examples include:

- 1. For female patients, all of the criteria for Anorexia Nervosa are met except that the patient has regular menses.
- 2. All of the criteria for Anorexia Nervosa are met except that, despite significant weight loss, the patient's current weight is in the normal range.
- 3. All of the criteria for Bulimia Nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur less than twice a week or for less than 3 months.

## ***Introduction section***

4. The patient has normal body weight and regularly uses inappropriate compensatory behavior after eating small amounts of food (e.g., self-induced vomiting after consuming two cookies).
5. The patient engages in repeatedly chewing and spitting out, but not swallowing, large amounts of food.
6. Binge-eating disorder: recurrent episodes of binge eating in the absence of regular inappropriate compensatory behavior characteristic of Bulimia Nervosa.

A recent version of the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V; American Psychiatric Organization, 2013) presents a number of changes with regards to the diagnosis of EDs in order to better represent the symptoms and behaviors of patients suffering from these conditions across the lifespan.

- Regarding AN, amenorrhea has been removed as a requirement for diagnosing anorexia in women, as it cannot be applied to males, pre-menarchal females, females taking oral contraceptives and post-menopausal females. Additionally, the word “refusal” of Criterion A was removed because it implied intention on the part of the patient and was difficult to assess. Criterion B has also been expanded to include not only “intense fear of weight gain”, but also “persistent behavior that interferes with weight gain”.
- Regarding BN, DSM-V criteria have reduced the frequency of binge eating and compensatory behaviors that people with BN must exhibit to just once a week.
- Whereas BED was included as an example of EDNOS in the DSM-IV, it now has its own diagnostic label that includes the same description of the disorder that was found in the DSM-IV (i.e. recurrent episodes of binge eating in the absence of regular inappropriate compensatory behavior characteristic of BN). However, the DSM-V states that the minimum average frequency of binge eating has been changed from at least twice weekly for 6 months to at least once weekly over the last 3 months. Therefore, the following criteria are used to establish a diagnosis of BED:
  - A. Recurrent episodes of binge eating (same as BN).
  - B. Binge eating episodes are associated with three (or more) of the following: (1) eating much more rapidly than normal, (2) eating until feeling uncomfortably full, (3) eating large amounts of food when not feeling physically hungry, (4) eating

alone because of embarrassment, (5) feeling disgusted with oneself, depressed, or very guilty after overeating.

- C. Marked distress regarding binge eating is present.
- D. At least once a week for 3 months.
- E. The binge eating is not associated with the recurrent use of inappropriate compensatory behavior.

The above-mentioned diagnostic categories provide a common language for communication between mental health professionals and they are therefore considered crucial for clinical practice and investigation. However, longitudinal stability of ED symptoms and behaviors may be questioned given that the clinical picture of patients may change over time and patients tend to migrate continuously across the three diagnostic categories. The transdiagnostic model of EDs (Fairburn, Cooper, & Shafran, 2008) is a sign of the effort being made to resolve the above mentioned problems. Fairburn and colleagues affirm the following: “What is most striking about AN, BN, and EDNOS, is not what distinguishes them, but how similar they are”. The model, using a dimensional perspective on EDs, postulates that among ED subtypes there are shared psychopathological processes of over-evaluation of shape, body and weight, as well as a desire to control them, but they each present distinctive clinical behaviors and symptoms (strict dieting, binge eating, purging behaviors). Consequently, interventions should target significant behaviors and clinical manifestations of the disorder rather than the patient’s specific ED diagnosis.

#### **1.4. Summary of Chapter**

This chapter has offered a brief introduction to ED prevalence, prognosis, etiology and their adverse consequences. Both DSM-IV and DSM-V diagnostic criteria for establishing ED diagnosis have also been presented. Notwithstanding, the different samples collected in the papers that will be presented below were classified following DSM-IV criteria. Finally, an attempt to widen the scope of the debate on the categorical versus the dimensional perspective on EDs has been made.



## **CHAPTER 2. FAMILY CAREGIVING IN EATING DISORDERS**

### **2.1. Introduction to Chapter**

The chapter provides an introduction to family caregiving among several psychiatric illnesses, and then focuses more specifically on the growing literature on the caregiving experience of families of persons with an ED. Results of several quantitative studies assessing the caregiving strain in the UK and in Spain are presented. Finally, an exploratory model of carer distress is described, which will be analyzed in more detail in Chapter 3.

### **2.2. Introduction to Family Caregiving**

Carers of people with mental health difficulties experience high levels of distress, burden and psychological morbidity, inconclusively associated with demographic and illness-related factors (Baronet, 1999). Caring for a loved one with a mental disorder has been directly associated with an important deterioration of carers' physical and mental health (Brown & Rutter, 1966). Most of the research on caregiving has been focused on carers of patients with schizophrenia (Barrowclough & Parle, 1997) and Alzheimer's disease (Tarrier et al., 2002). In the case of schizophrenia, Expressed Emotion (EE) has been considered a core factor associated with the outcome and maintenance of the illness. In Alzheimer's disease, most of the strain related to family caregiving has been associated with the challenges and demands inherent in the illness and the deterioration it brings in the sufferer's functioning, as well as with the subsequent loss of the patient's personality and his/her relationship with the carer.

### **2.3. Family caregiving in Eating Disorders**

In EDs, the family of origin is deeply involved in the recovery process of their loved one, in light of the severity of the disorder and its early onset in late childhood. Moreover, there may be additional difficulties associated with the developmental "inappropriateness" of caring for an increasingly dependent adult child (Treasure et al., 2001) or caring for a treatment-resistant patient who may deny the seriousness of his/her illness (Strober, 2004). All of these features may make the nature of the caregiving experience in EDs very stressful and demanding.

The study of caregiving strain in EDs has been a relatively unknown area until the last decade. A scientific team in the ED Unit at the Maudsley Hospital in London, UK is currently the group of researchers with the most dedication to examining these variables. Clinical experience and research have shown that carers experience a variety of negative feelings, among them lack of understanding, self-blame, shame, helplessness and despair at managing ED behaviors and at communicating with their relative (Perkins, Winn, Murray, Murphy, & Schmidt, 2004; Winn, Perkins, Murray, Murphy, & Schmidt, 2004) and they also show high levels of distress, burden and mental health difficulties (Whitney, Haigh, Weinman, & Treasure, 2007). Furthermore, they acknowledge a need for help and guidance from professionals (Haigh & Treasure, 2003; Whitney et al., 2005).

Recent quantitative research on factors associated with emotional well-being among carers suggests that the fear of long-term dependency and the feelings of stigma and isolation may increase psychological distress among carers (Dimitropoulos, Carter, Schachter, & Woodside, 2008; Whitney et al., 2007).

In Spain, there has been an increasing number of studies on family caregiving in EDs. Most of the existing studies are cross-sectional and have focused on familial risk factors which may be associated with a negative caregiving experience in EDs, among them, the study of dyadic adjustment (Espina, Ochoa de Alda, & Ortego, 2003), EE (Medina-Pradas et al., 2011b; Rodriguez & Vaz, 2005), psychological distress and personality features of carers (Ochoa de Alda & Espina, 2006). Additionally, one study explored differences in psychological distress among primary and secondary carers of ED patients (Berbel et al., 2010) and a more recent one by the same research group moved towards the identification of predictors of emotional well-being among primary carers (Sepúlveda et al., 2012). The ED research team in Bizkaia, Spain, directed by Angel Padierna, has offered some advances in research on health-related quality of life of ED carers and some interesting findings regarding predictors of change in their mental health (González, Padierna, Martín, Aguirre, & Quintana, 2012; Martin et al., 2011; Orive et al., 2013). Finally, a recent pilot study presented the longitudinal results of a new structured psycho-educational intervention program for relatives of patients with an ED (Gutiérrez, Sepúlveda, Anastasiadou, & Medina-Pradas, 2014).

Several models have been proposed in order to better understand the way in which the caregiving experience and psychological distress of carers may be linked together

and also their role as predictors of better illness outcome (Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990). The model of Schene, van Wijngaarden, & Maarten (1998), adapted for ED carers by Winn and colleagues (2007), is the one that best contextualizes the above-mentioned relationship, by also highlighting the importance of preceding factors associated with patient and carer characteristics as well as interpersonal elements of the relationship between them. There will be a more detailed description of this model in the next chapter.

## **2.4. Summary of Chapter**

The chapter has briefly introduced the concept of family caregiving in several psychiatric illnesses and has then focused on studies examining the experience of caring for a loved one suffering from an ED. The literature in Spain studying factors associated with family caregiving in EDs is increasing, although the lack of studies examining the efficiency of family-based interventions is evident in our country. Lastly, a need for an explicative model to better understand how different familial risk factors are linked together and may influence illness outcome, is highlighted at the end of the chapter.

## **CHAPTER 3. THE ROLE OF THE FAMILY IN THE DEVELOPMENT AND MAINTENANCE OF EATING DISORDERS**

### **3.1. Introduction to Chapter**

According to the modern biopsychosocial model of mental illness (Engel, 1977) a strong association has been observed between individual psychopathology and family dysfunction. However, the exact mechanisms of interaction between family functioning and mental illness, as well as the direction of this relationship, have not been adequately delineated. The present chapter historically reviews the evolution of research on the role of the family in the development and maintenance of EDs, moving from the pursuit of causal explanations to the development of non-blaming theories which target the interpersonal maintaining mechanisms of the illness. Lastly, the need to view families as a resource in treatment is discussed.

### **3.2. Historical evolution of the role of the family in the development and maintenance of Eating Disorders**

The central role of families in EDs can be traced back as far as the 19<sup>th</sup> century. Taking as an example the work of Gull (1874) and Charcot (1889), families were traditionally blamed for their children's problematic patterns of functioning and were considered a hindrance to treatment. During the 1970's, new conceptual models were developed, according to which EDs developed out of a particular family system with specific characteristics. For example, in the presence of the enmeshed, overprotective and rigid families, first described by Minuchin and colleagues (Minuchin, Rosman & Baker, 1978), recovery may be achieved only by changing the pathological family system in which the child may use the symptoms as a form of communicating family conflict. In turn, the systemic-strategic view of Selvini-Palazzoli (1974) followed the Minuchin's psychosomatic family model and also identified faulty communication patterns among family members, which made them deeply resistant to interventions. Both models were poorly supported by empirical evidence and were considered unconvincing and conceptually flawed (Eisler, 2005; Vandereycken, 2002).

More recently, Dare & Eisler (1995) and Schmidt & Treasure (2006) have described a new theoretical framework that states that a deeper understanding of the maintaining mechanisms of the disorder, which includes dysfunctional patterns of family

functioning, is likely to be of more scientific and clinical utility than the pursuit of causal explanations.

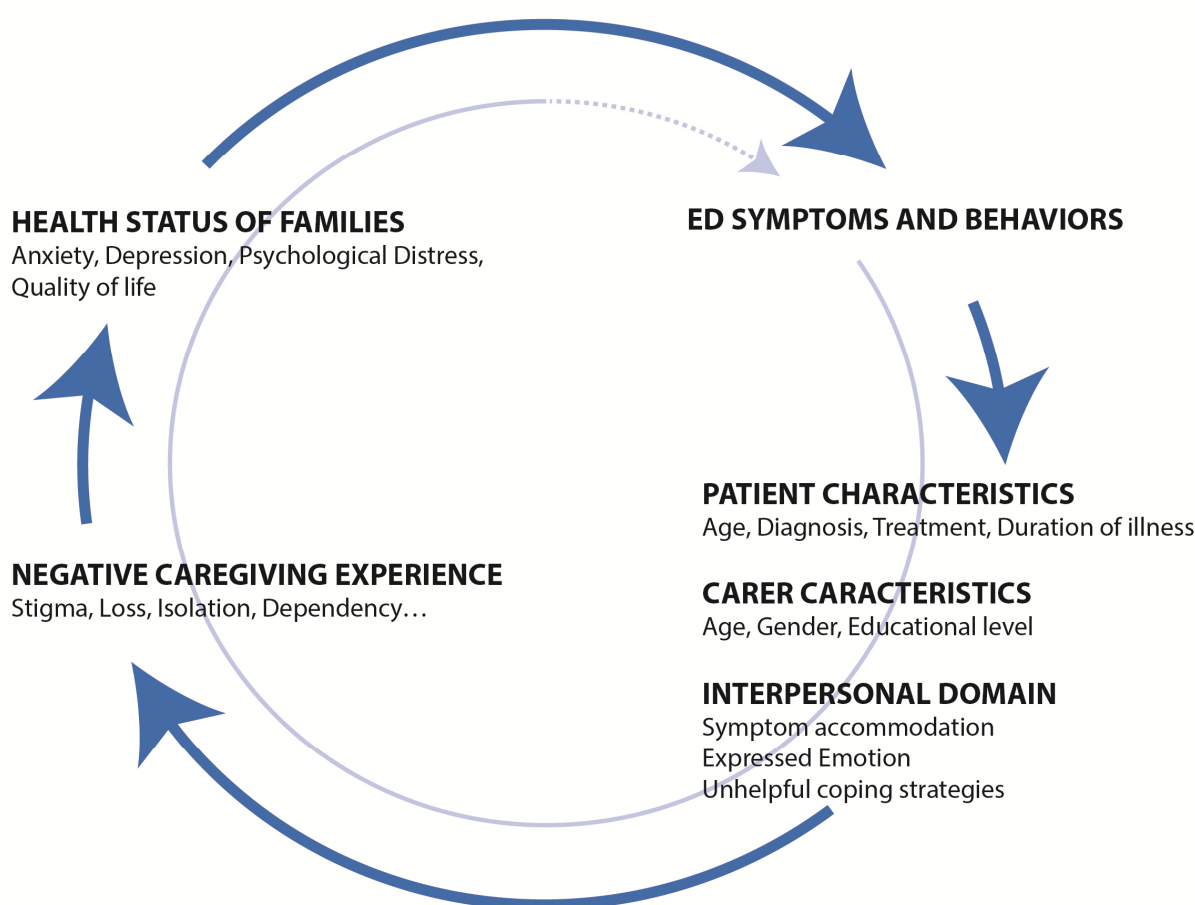
### **3.3. The interpersonal maintenance model in Eating Disorders and its significance in family therapy**

Recent studies have described the complex way in which interpersonal relationships become entangled with the ED. The re-organization of family life around the symptoms, the extreme focus of the families on the *here and now* instead of being able to view the *bigger picture* or their inability to move away from using unhelpful response patterns to the illness may serve as maintenance factors for the disorder and lead to a more burdensome caregiving experience within the family (Coomber & King, 2012a, 2013b; Eisler, 2005; Goddard et al., 2011; Whitney et al., 2005). Monteleone and colleagues (2005) identified three common types of unhelpful family reactions to the illness, considered maintenance mechanisms of the disorder:

- 1) It is common for carers to feel anxious or depressed, with feelings of self-blame, worthlessness and perceived stigma from others, while at the same time being inefficient and far from finding a solution to the problem.
- 2) Alternatively, many carers may feel frustrated by the unproductive conflicts around food and weight or the illogical arguments put forth by the patient and may end up adopting increased critical, hostile and over-controlling responses.
- 3) Last but not least, in their attempt to alleviate family conflict and personal distress, carers may find themselves stuck in a pattern of exhibiting accommodating and enabling behaviors. These behaviors, in turn, may allow ED symptomatic behaviors, such as rule bound eating and weight and shape control behaviors, to continue and thereby they negatively influence the patient's outcome (Sepúlveda, Kyriacou, & Treasure, 2009). Feeling that they have to do all they can to care for their son/daughter, they find themselves in "compulsive caring" mode, which makes patients even more dependent and demanding.

According to the interpersonal maintenance model in EDs, the distressing patterns of the interpersonal interaction within the family are considered clinically valuable, given that they are core perpetuating processes in the maintenance of EDs (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). More specifically, carers' unhelpful behaviors and emotions characterized by high levels of EE, accommodating and enabling

behaviors or unhelpful coping mechanisms, may increase distress in carers and in turn, allow ED symptoms to flourish (Figure 1). At this point, a vicious cycle begins, maintaining the illness and its symptoms. Recent findings that support this model and its trans-diagnostic application have shown that dysfunctional interactions within the family are associated with more negative family caregiving (Goddard et al., 2011; Sepúlveda et al., 2010; Winn et al., 2007) and a slower rate of recovery in patients (van Furth et al., 1996).



**Figure 1.** The interpersonal maintenance model in EDs (Schmidt & Treasure, 2006)

Current evidence adds support to the need to conceptualize families as a resource in treatment and as an ally against the illness, as long as their strengths and needs are properly addressed. Furthermore, the involvement of carers in treatment is a reflection of good practice in terms of the recommendations provided by the National Institute of Health and Care Excellence (NICE) guidelines (NICE, 2004). According to the new non-blaming approach to family treatment (Schmidt & Treasure, 2006), families are not considered part of the problem, but part of its solution. Thus, the above-mentioned

interpersonal maintenance factors are considered therapeutic targets in family therapy and predictors of a better prognosis of the illness. However, there is a scarcity of studies that replicate the association between them (Uehara, Kawashima, Goto, Tasaki, & Someya, 2001).

### **3.4. Summary of Chapter**

The chapter has briefly reviewed the role of family in the development and maintenance of EDs concluding that, the pathological family systems described by Minuchin et al. (1978) and Selvini-Palazzoli (1974) and the research that was born in the wake of these theories, is unconvincing and conceptually flawed. Afterwards, the interpersonal maintenance model in EDs has been introduced, according to which family members, in their attempt to fight against the ED often get stuck in unhelpful patterns of response which act as maintaining factors of the illness. Therefore, families may be conceptualized as a resource in treatment once the interpersonal maintenance factors are identified, expressed by them and targeted in family therapy.

## **CHAPTER 4: EXPRESSED EMOTION**

### **4.1. Introduction to Chapter**

EE is introduced in this chapter, providing a historical overview of the construct and then summarizing its five basic components. The role of EE as a key maintenance factor in EDs is then discussed and results of recent studies that explore the connection between the emotional environment at home and carers' well-being or illness outcome are presented. Possible gender differences in carers' EE are also considered and a brief discussion about patient's characteristics that may influence carers' perceptions of EE is later presented. The next section focuses on the assessment of EE and provides five alternative measures which have been widely used in research and clinical settings to assess the emotional climate at home among carers. The results of a systematic review of studies assessing EE among ED samples are then presented. Afterwards, the current situation of validated instruments in Spain is briefly discussed and recommendations about the direction of future validation research on EE are also provided. The chapter ends with a brief presentation of the results of family-based interventions aimed at reducing levels of EE among carers.

### **4.2. Expressed Emotion: Background and construct**

EE is one of the most widely used constructs among various psychiatric illnesses to reflect the emotional climate at home. The concept of EE was first identified in the 60's, in relation to the research between social factors and relapse in schizophrenia. Brown and his colleagues pointed out that in "high emotional involvement" homes patients are more likely to relapse, while a long-term decrease in emotional involvement among relatives is associated with an improvement of symptom severity in patients (Brown, Birley, & Wing, 1972). Years later, the meta-analysis of Butzlaff & Hooley (1998) confirmed that high EE was a reliable predictor of relapse in schizophrenia and was associated with poor outcome in other psychiatric conditions, including EDs.

A family characterized by high levels of EE is one in which the relatives tend to be critical, hostile and/or emotionally overinvolved toward the patient. The emotional climate at home has also received a positive connotation, although this aspect has not been so widely used among family studies. EE was traditionally evaluated based on verbal information obtained by the semi-structured Camberwell Family Interview (CFI;



Brown & Rutter, 1966; Vaughn & Leff, 1976b) together with non-verbal behavior of the family member during the interview (crying, dramatization, etc.). Brown and colleagues (Brown & Rutter, 1966; Brown et al., 1972) offered definitions and examples of the five main components of EE that best describe the emotional climate at home:

**a) Critical Comments (CC):**

For a remark to be judged critical in content there had to be a clear and unambiguous statement of resentment, disapproval or dislike expressed by the family member towards the patient. Critical comments were judged either by the tone of the voice or by the content of what was said by the family member.

**b) Hostility (H):**

Hostility was present when a remark was made indicating the rejection of someone as a person, also reflecting a generalized negative evaluation of a person; for example, when someone was criticized for what he was rather than for what he did. Hostility was also present if critical comments tended to be spontaneously generalized; for example, when someone's critical comment triggered further criticisms on unrelated topics.

**c) Emotional Overinvolvement (EOI):**

Emotional Overinvolvement was present when a family member expressed unusually marked concern, disproportionate protective attitudes and attempts to exercise control over the patient's behavior. Also, it was present when the relative expressed obvious and constant anxiety and feelings of hopelessness and self-sacrifice.

**d) Warmth (W)**

Expression of warmth was present when a remark reflected sympathy, concern, understanding and interest in the other as a person or expressed an enjoyment in mutual activities. Warmth was also assessed by the tone of voice of the person talking.

**e) Positive Remarks (PR)**

Positive Remarks reflected the expressions of approval and appreciation of the patient or his/her behavior.

It is worth noting that family warmth and positive remarks have received little attention (Brown et al., 1972). Only a few studies with samples of patients with

psychosis, schizophrenia or bipolar disorder have explored the role of warmth and positive remarks as protective factors against relapse, and their relationship with an improvement of the illness outcome (Ivanovic et al., 1994; López et al., 2004; Miklowitz, 2006).

### **4.3. Expressed Emotion in Eating Disorders**

Research focused on the interpersonal factors proposed by the Maudsley maintenance model has considered EE to be a key maintenance factor that may influence the outcome of EDs (van Furth et al., 1996), the relapse rate of patients (Szmukler, Eisler, Russell, & Dare, 1985) and also their response to treatment (Eisler et al., 2000). Qualitative evidence suggests that parents of patients with AN can become critical because of their erroneous illness appraisals, whereas the fear of the negative consequences of the disorder may lead them to adopt an overprotective attitude towards their son/daughter (Whitney et al., 2005).

Studies exploring the connection between the emotional environment at home in EDs and carers' well-being have increased in interest in recent years. High EE was associated with large number of face-to-face hours with the patient, supervising his/her eating habits and medical health status (Winn et al., 2007). EE was also found to be associated with increased levels of distress and a negative caregiving experience among AN and BN families (Hoste, Labuschagne, Lock, & Le Grange, 2012; Wearden, Tarrier, Barrowclough, Zastowny, & Armstrong Rahill, 2000; Winn et al., 2007). Additionally, the impact of EE on carer burden and psychological distress was found to be mediated by the maladaptive coping mechanisms they used (Coomber & King, 2012a).

In regards to gender differences in EE, mothers, especially in AN families, were more likely than fathers to adopt an attitude of emotional overinvolvement in their interactions with the patient (Anastasiadou, Cuellar-Flores, Sepúlveda, & Graell, 2014; Kyriacou, Schmidt, & Treasure, 2008a; Rodriguez & Vaz, 2005; Santonastaso, Saccon, & Favaro, 1997). In turn, fathers tended to be more emotionally overinvolved in their interactions with patients with BN as compared to AN patients (Kyriacou et al., 2008a; Szmukler et al., 1985). Finally, Szmukler and colleagues (1985) showed that a critical response of fathers towards the illness was associated with longer illness duration, as well as with treatment dropouts.

#### **4.4. Differences in relatives' perception of Expressed Emotion in relation to patients' characteristics**

In EDs there seems to be a connection between patients' characteristics (diagnosis, clinical features of the illness, duration) and levels of EE among relatives. For example, it was demonstrated that families of patients with AN tended to be more overprotective of their sons/daughters than healthy controls because of their anxiety and uncertainty concerning the severity of ED symptoms (Kyriacou et al., 2008a). In turn, in families of people with BN, frustration and criticism were more common responses (Winn et al., 2007). Following the dimensional perspective of EDs, there have not been any studies examining the impact of ED specific behavioral disturbances on the levels of EE among relatives. The available literature that has examined differences in well-being between carers of AN patients with and without binge eating behaviors, suggests that the family environment of the first group of patients presents greater conflict and negativity, less cohesion and structure and greater psychopathology than the second one (Strober, 1981; Viesselman & Roig, 1985). Finally, in regards to illness duration, higher levels of EE have been found among patients with longer illness duration (Sepúlveda et al., 2010).

In terms of comparison studies, parents of patients with AN reported higher levels of EOI and CC than parents of healthy controls (Kyriacou et al., 2008a), but lower than parents of patients with schizophrenia (Hodes & Le Grange, 1993). Additionally, mothers of patients with AN were more emotionally involved than mothers of patients with cystic fibrosis (Blair, Freeman, & Cull, 1995). Finally, fathers and mothers of patients with AN expressed less CC than relatives of patients with substance-related disorders (Anastasiadou, Parks, Sepúlveda, Sánchez, & Graell, 2014).

#### **4.5. Assessment of Expressed Emotion among families**

The thorough literature review of EE measures by Van Humbeeck, Van Audenhove, De Hert, Pieters, & Storms (2002) and the more recent and specific one regarding families of patients with EDs by Duclos, Vibert, Mattar, & Goddard (2012) present a variety of alternative measures which have been widely used in research and clinical settings (Table 1).

EE was traditionally assessed by the *Camberwell Family Interview* (CFI; Brown & Rutter, 1966) which is an audiotaped, semistructured interview with a duration of approximately 5 hours, and later by a modified shortened version of the interview that

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required around 2 hours to complete (Vaughn & Leff, 1976b). The CFI is administered to the key relative and is scored by a trained interviewer. It has shown good psychometric properties and a strong predictive validity for relapse in samples of patients with schizophrenia (Butzlaff & Hooley, 1998). However, the CFI presented several shortcomings, among them, the length of time required for its administration by a trained interviewer (1–2h), additional time for its coding by an experienced rater (additional 3h) and the need for a 2-week training period for raters. All these factors led researchers to look for less time-consuming alternatives. In this manner, the *Standardized Clinical Family Interview* (SCFI; Kinston & Loader, 1984) was developed, an interview derived from the CFI that was applied to the entire family together. However, the SCFI has not been widely used among ED samples. The *Five Minute Speech Sample* (FMSS; Magaña et al., 1986) was developed a few years later as a shorter alternative for the assessment of EE and was originally used among families of patients with schizophrenia. Although the FMSS is less time-consuming than the CFI (it consists of an audio taped 5-minute monologue of the key relative), it underestimates the score of the CFI in 20–30% of the samples. Additionally, the predictive validity of the instrument continues to remain unclear (Van Humbeeck et al., 2002).

Three self-report questionnaires have been used to assess the EE experienced by relatives of patients with an ED. The *Level of Expressed Emotion* scale (LEE; Kazarian, Malla, Cole, & Baker, 1990) was first developed to assess EE perceived by patients with schizophrenia, showing satisfactory psychometric properties of internal consistency and test-retest reliability, good predictive validity for relapse (Cole & Kazarian, 1993) and good concurrent validity with the CFI (Kazarian et al., 1990). When the patients' and the new relatives' version of the LEE were used together among samples of Mexican-American and Caucasians with schizophrenia, no differences in the perceptions of EE were found between patients and their family members. The cultural sensitivity of the LEE has also been discussed (Kopelowitz et al., 2002). Although the relative version of the LEE has been used in several studies with relatives of patients with schizophrenia (Kopelowitz et al., 2002) or Obsessive Compulsive Disorder (van Noppen & Steketee, 2009), this version of the questionnaire is still in need of further validation.

The *Family Problems Questionnaire* (FPQ) was developed by Morosini, Roncone, Veltro, Palomba, & Casacchia (1991). The questionnaire has only been used with ED samples in the preliminary study of Santonastaso et al. (1997) in which family burden was

evaluated. The *Family Questionnaire* (FQ) was developed by Wiedemann, Rayki, Feistein, & Hahlweg (2002) as a more cost-effective and research-applicable method for assessing EE, compared to the CFI (Duclos et al., 2012) and to the FMSS (Möller-Leimkühler, 2005). The instrument was first used with a sample of relatives of patients with schizophrenia showing good internal consistency and better concurrent validity with the CFI than any other short EE instrument.

At this point, two major issues related to the assessment of EE in EDs should be mentioned: On one hand, regarding the advantages of self-report instruments compared with interviews, we can mention their easy and less time-consuming administration and the possibility of using them over time with more complex research and clinical settings (i.e. pre-post-follow-up designs) or when large samples of patients and relatives are required. We can also assume that the effect of social desirability is more common in interviews considering that the individual is more likely to suppress socially unacceptable behaviors during the interview.

On the other hand, concerning the question “which family member better perceives and reflects the family environment at home, the patient or the relative?” we can hypothesize that the relative’s perceptions of EE are more valid than the patient’s perceptions, especially among samples of patients with EDs. One possible reason behind this assumption could be due to aspects of the nature of the illness itself: Patients with EDs are often characterized by high levels of secrecy, lying and deception behaviors, they are often resistant to treatment and they present problems in recognizing their own emotions as well as emotions of others (Zonnevijlle-Bendek, van Goozen, Cohen-Kettenis, van Elburg, & van Engeland, 2002). Thus, it can be assumed that their mothers and fathers may be more reliable and objective informers of the emotional experiences at home. This can also be confirmed by the fact that the convergent validity of the instrument with the criticism subscale of the CFI was found to be satisfactory only with the relative version of the LEE scale and not with the patient version (Kazarian et al., 1990). Therefore, the conceptualization of EE from the relative’s point of view may be more appropriate than a patient-focused approach (Vaughn & Leff, 1976b).

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**Table 1.** Instruments assessing Expressed Emotion among ED families (adapted from Humbeeck, Van Audenhove, De Herta, Pieters, & Storms, 2002)

<i>Interview</i>	<b>Validation Study</b>	<b>Measure</b>	<b>Subscales</b>	<b>Nº items</b>	<b>Rating scale</b>	<b>Score Range</b>	<b>Cut-off scores</b>	<b>Reliability</b>	<b>Validity</b>	<b>Sample type (N)</b>
	Brown & Rutter (1966) Vaughn & Leff (1976b) (Spanish version: Rodríguez & Vaz, 2005; EDs sample)	Camberwell Family Interview (CFI) – shortened	1) Critical Comments 2) Hostility 3) Emotional Overinvolvement 4) Warmth 5) Positive Remarks	-	Frequency count 0,1,2 or 3 0-5 Frequency count	-	CC≥ 6 H≥ 1 EOI≥ 3	<u>Internal Consistency</u> ≥ 0.80  <u>Inter-rater</u> r= 0.85	<u>Predictive</u> (relapse) ≥ 0.30, p= 0.001	Young patients with schizophrenia and relatives (110)
	Kinston & Loader (1984)	Standardized Clinical Family Interview (SCFI)	1) Critical Comments 2) Hostility 3) Emotional Overinvolvement 4) Warmth 5) Positive Remarks	-	Frequency count 0,1,2 or 3 0-5 Frequency count	-	CC≥ 6 H≥ 1 EOI≥ 3	<u>Inter-rater</u> r= 0.30-1.00		Family interview (relatives, patients, siblings) (17)
	Gottschalk & Gleser (1969) Magaña et al. (1986) (Spanish version: Muela & Godoy, 2010; schizophrenia sample)	Five Minute Speech Sample (FMSS)	1) Criticism 2) Emotional Overinvolvement	-		-	CC≥ 1 EOI≥ 3	<u>Internal Consistency</u> ≥ 0.80  <u>Inter-rater</u> κ= 0.6-1.0  <u>Test-retest</u> r= 0.64	<u>Predictive</u> When borderline group is a part of the high-EE group ( $\chi^2= 6.59$ ; df= 1, p< .02) <u>Concurrent</u> CFI: 20-30% underestimation	Key relative of patients with schizophrenia (74)
<i>Self-report</i>	Cole & Kazarian (1988) (patient version)  Kazarian, Malla, Cole, & Baker (1990) (relative version)	Level of Expressed Emotion (LEE)	1) Intrusiveness 2) Emotional response 3) Negative attitude towards illness 4) Tolerance	60	True/False Response	0-60	≥ 9: need for further replication	<u>Internal Consistency</u> 0.84-0.89  <u>Test-retest</u> r= 0.67-0.82	<u>Concurrent</u> : CFI: CC (CFI) and Intrusiveness (LEE) (r= .40, p< .05) and Tolerance (LEE) (r= .40, p< .05) CC (CFI) and Negative Attitude (LEE) (r= .49, p< .05) W (CFI) and Negative Attitude (LEE) (r= -.41, p<.05)	Patients with schizophrenia and their relatives
	Wiedemann, Rayki, Feistein, & Hahlweg (2002)	Family Questionnaire	1) Criticism 2) Emotional Over involvement	20	1-4	10-40 for each subscale	CC≥ 23 EOI≥ 27	<u>Internal Consistency</u> 0.80-0.92	<u>Concurrent</u> : <u>LEE mothers</u> : LEE-Total (LEE) and CC (FQ) (r= .64, p< .00), EOI (FQ) (r= .39, p< .05)	Relatives of patients with schizophrenia (79)
	Morosini, Roncone, Veltro, Palomba, & Casacchia (1991)	Family Problems Questionnaire (FPQ)	1) Hypercriticism 2) Overinvolvement 3) Subjective burden 4) Objective burden					<u>Internal Consistency</u> 0.90		Key relative of patients with schizophrenia

#### **4.6. Assessment of Expressed Emotion among relatives of patients with an Eating Disorder: A review of the literature and current situation**

In Table 2, outcomes of a thorough review of studies published from 2008 to 2013 that assess EE among ED samples are presented (Anastasiadou, Medina-Pradas, Sepúlveda, & Treasure, 2014). Taking a closer look at the table, it can be noted that ED carers expressed high levels of EE, particularly EOI, with mothers being more emotionally over-involved with their sons/daughters than fathers, who tended to be more critical. It is worth highlighting that the subjective appraisal of the emotional climate at home was more negative compared with the objective one given by trained interviewers, i.e. carers tended to perceive themselves as more critical and emotionally over-involved than the clinicians did. From a clinical point of view, having to share their private negative experiences at home with an interviewer may lead carers to lessen the intensity of their discomfort or to conceal the real picture of their experience, as an effect of social desirability. No association between EE and patient's characteristics (illness duration or ED diagnosis) was observed in the table, contrary to previous findings of Kyriacou, Treasure, & Schmidt (2008a) and Sepúlveda et al. (2010).

Regarding EE assessment, Table 2 shows that there is a lack of relevant research studies using self-report instruments among ED populations. In addition, the two available self-report instruments -FQ and LEE- have not been psychometrically tested enough and have not been further translated and used in transcultural studies.

In regards to the current situation of instrument validation in Spain, at the present moment there are not any self-report instruments assessing EE of relatives which are translated and validated in the Spanish population. In terms of interviews, the Camberwell Family Interview (Rodríguez & Vaz, 2005) and the Five Minutes Speech Scale (Muela & Godoy, 2010) have been adapted for use in clinical samples in Spain but they have not been widely used in further studies among other clinical populations in Spain. Given the absence of measures validated and used in clinical samples in Spain, it is difficult to evaluate treatment outcomes, especially outcomes of family interventions based on the Maudsley maintenance model in EDs, which mainly point to EE as a key maintenance factor.

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**Table 2.** Descriptive data of patients, carers and outcomes of the studies assessing Expressed Emotion (CFI, SCFI, FMSS, LEE, FQ) (copied from the table presented in the article by Anastasiadou, Medina-Pradas, Sepúlveda, & Treasure, 2014)

STUDY	PATIENTS				CARERS					SCORES*		
	N	Age (Mean, SD)	ED diagnosis (%)	Illness duration in years (Mean, SD)	N	Type of relative (%)	Gender (%)	Living with sufferer (%)	>21 contact hours per week (%)	Measure	EE Indices (Mean, SD)	High-EE (%)
Medina-Pradas, Navarro, Lopez, Grau, & Obiols (2011b)	77	26.4 (7.3)	AN= 46.7 BN= 31.2 EDNOS= 22.1	8.8 (6.6)	77	Mother= 70.1 Father= 5.2 Other= 24.7	F= 72.7 M= 27.3	79.2	81.8	CFI	CC= 5.0 (3.8) EOI= 1.9 (0-5) W= 3.21 (0-5) PR= 3.0 (2.4)	49.4 High-CC: 33.8 High-EOI: 28.6
Hoste, Labuschagne, Lock, & Le Grange (2012)	189	14.7 (1.6)	AN= 100	0.9 (0.8)	344	Mother= 53.5 Father= 46.5	F= 53.5 M= 46.5	100	NR	SCFI	CC: Fathers= 0.4 (1.0) Mothers= 0.5 (1.7) EOI: Fathers= 0.4 (0.7) Mothers= 0.8 (1.0) W: Fathers= 1.5 (1.3) Mothers= 2.1 (1.2) PR: Fathers= 1.0 (1.3) Mothers= 1.6 (1.7)	17 High-CC: Mothers= 2.7 Fathers= 0.6 High-EOI: Mothers= 8.2 Fathers= 1.9
Duclos, Maria, Dorard, Curt, Apfel, Vibert, et al. (2012)	60	16.6 (1.6)	AN= 91.7 Other= 8.3	1.38 (0.6)	118	Mother= 50.8 Father= 49.2	F= 50.8 M= 49.2	100	NR	FMSS	NR	Mothers= 51.7 Fathers= 49.1 High-CC: Mothers= 24.1 Fathers= 27.3 High-EOI: Mothers= 36.2 Fathers= 34.5
Grover, Williams, Eisler, Fairbairn, McCloskey, Smith, et al. (2011)	27	28 (9.5)	AN-R= 70.4 AN-P= 18.5 EDNOS= 7.4 Recovered= 3.7	7.1 (8.4)	27	Mother= 63 Father= 11.1 Other= 25.9	NR	77.8	NR	FMSS	NR	37
Sepúlveda, Todd, Whitaker, Grover, Stahl, & Treasure (2010)	45	21.5 (5.3)	AN= 77.8 BN= 22.2	3.07 (3.1)	47	Mother= NR Father= NR Other= 4.3	F= 91.5 M= 8.5	76.1	62.2	FMSS	NR	55.3 High-CC: 19.1 High-EOI: 36.2
Gisladdottir & Svavarsdottir (2011)	14	21 (NR)	AN= 21.4 BN= 57.2 EDNOS= 7.1 NR= 14.3	NR	24	Mother= 48 Father= 28 Other= 24	NR	NR	NR	LEE	12.3 (9.5)	NR



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STUDY	PATIENTS				CARERS					SCORES*		
	N	Age (Mean, SD)	ED diagnosis (%)	Illness duration in years (Mean, SD)	N	Type of relative (%)	Gender (%)	Living with sufferer (%)	>21 contact hours per week (%)	Measure	EE Indices (Mean, SD)	High-EE (%)
Grover, Naumann, Mahammad-Dar, Glennon, Ringwood, Eisler, et al. (2011)	63	20.4 (6.2)	AN-R= 60.3 AN-P= 17.5 EDNOS= 20.6 NR= 1.6	4.3 (4.5)	63	Mother= 79.4 Father= 7.9 Other= 12.7	NR	77.8	NR	LEE	11.1 (9.6)	NR
Grover, Williams, Eisler, Fairbairn, McCloskey, Smith, et al. (2011)	27	28 (9.5)	AN-R= 70.4 AN-P= 18.5 EDNOS= 7.4 Recovered= 3.7	7.1 (8.4)	27	Mother= 63 Father= 11.1 Other= 25.9	NR	77.8	NR	LEE	12.5 (6.6)	NR
Coomber & King (2012a)	56	21.5 (8.7)	AN= 67.9 BN= 12.5 BE= 1.8 Combination= 10.7 NR= 7.1	5.1 (5.0)	56	Parent= 75 Other= 25	F= 78.6 M= 21.4	78.5	NR	FQ	CC= 25.8 (5.8) EOI= 31.1 (3.4)	High-CC: 73.2 High-EOI: 89.3
Gisladdottir & Svavarsdottir (2011)	14	21 (NR)	AN= 21.4 BN= 57.2 EDNOS= 7.1 NR= 14.3	NR	24	Mother= 48 Father= 28 Other= 24	NR	NR	NR	FQ	CC= 21.7 (4.8) EOI= 24.8 (5.0)	NR
Goddard, Macdonald, Sepúlveda, Naumann, Landau, Schmidt, et al. (2011)	142	20.9 (9.7)	AN= 85.9 BN= 8.5 EDNOS= 5.6	3.5 (9.9)	153	Mother= 85 Father= 5.9 Other= 9.2	F= 88.9 M= 11.1	76.5	58.2	FQ	CC= 23.2 (5.6) EOI= 28.4 (4.4)	High-CC: 53.1 High-EOI: 66.7
Merwin, Zucker, & Timko (2013)	6	14.5 (1.5)	AN= 100	0.6 (0.2)	11	Mother= 45.5 Father= 36.4 Other= 18.1	F= 54.5 M= 45.5	100	NR	FQ	CC= 21.2 (6.9) EOI= 26.0 (5.5)	High-CC: 33 High-EOI: 44
Nilsson (2014)	32	15.1 (NR)	NR= 100	2.0 (NR)	54	NR	NR	100	NR	FQ	CC= 20.5 (6.0) EOI= 25.9 (5.9)	High-CC: 29 High-EOI: 27
Pépin & King (2013)	11	20.1 (3.0)	AN= 63.6 BN= 18.2 Combination= 9.1 NR= 9.1	4.3 (3.5)	15	Mother= 73.3 Father= 26.7	F= 73.3 M= 26.7	80	NR	FQ	CC= 24.6 (7.0) EOI= 30.5 (2.6)	High-CC: 64.3 High-EOI: 85.7
Sepúlveda, Kyriacou, & Treasure (2009)	193	21.3 (6.8)	AN= 70.5 BN= 24.4 NR= 5.1	5.9 (5.9)	193	Parent= 90.7 Other= 9.3	F= 85.5 M= 14.5	78	60.6	FQ	CC= 23.4 (5.5) EOI= 28.2 (4.4)	High-CC: 56.1 High-EOI: 65.4
Tsiaka, Treasure, & Schmidt (2014)	81	25.9 (6.5)	AN= 28.5 BN= 54.3 BE= 16 EDNOS= 1.2	8.8 (NR)	112	Mother= 65.2 Father= 34.8	F= 65.2 M= 34.8	63.9	NR	FQ	CC= 21.6 (6.0) EOI= 27.3 (5.6)	High-CC: 36.7 High-EOI: 50.9

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**Acronyms:** CFI= Camberwell Family Interview, FMSS= Five Minutes Speech Sample, SCFI= Standardized Clinical Family Interview, LEE= Level of Expressed Emotion scale, FQ= Family Questionnaire, NR = Not Referred, AN= Anorexia Nervosa, BN= Bulimia Nervosa, AN-R= Anorexia Nervosa-Restrictive, AN-P= Anorexia Nervosa-Purgative, EDNOS= Eating Disorder Not Otherwise Specified, BE= Binge Eating Disorder, F= Female, M= Male, EE= Expressed Emotion, CC= Criticism, H= Hostility, EOI= Emotional Over-involvement, W= Warmth, PR= Positive remarks.

\*According to authors, in the CFI and SCFI, EE ratings possible ranges are as follows: CC (frequency count), H (0-3), EOI (0-5), Warmth (0-5), and Positive remarks (frequency count), and carers are defined as high-EE if:  $CC \geq 6$ ,  $H \geq 1$  or  $EOI \geq 3$ .

In the FMSS, EE ratings range at the same way than in CFI/SCFI (although CC and PR indices are not comparable due to different length of interviews), and carers are defined as high-EE if:  $CC \geq 1$ ,  $H \geq 1$  or  $EOI \geq 3$ .

The possible score range for the LEE total score is of 0-60. Carers are defined as high-EE if score  $\geq 9$ .

The possible score ranges are of 10-40 for both subscales of FQ (CC and EOI). Carers are defined as high-EE if  $FQ-CC \geq 23$  or  $FQ-EOI \geq 27$ .

#### **4.7. Expressed Emotion as a variable modifiable through family-based interventions**

Overall, it seems that EE of relatives is a valid construct in the field of EDs and can be reduced through family-based interventions. The first interventions including family members in the treatment process were psycho-educational (Garner, 1985) and viewed carers as educators/co-therapists who helped their loved one to face the maintenance factors of his/her illness. These interventions have proved to be useful in decreasing the EE levels of the family (Sepúlveda et al., 2010; Uehara et al., 2001; van Furth et al., 1996).

Most of the recent research on family interventions is encompassed within the Maudsley model of family therapy. Interventions based on this model can be beneficial for carers in that they increase their knowledge and understanding of the illness, and as a result, improve their feelings of self-efficacy. They can also help carers to enhance communication skills and empathy with the patient. In addition, by targeting specific unhelpful interactional styles within the family, family interventions can reduce CC and EOI of carers (Pépin & King 2013) and can increase their strengths and feelings of warmth towards their loved one (Eisler et al., 2000).

Up until now, four Randomized Controlled Trials (RCT) have been published examining the effectiveness of Maudsley family therapy, and have shown a significant decrease in EE and an improvement of the interpersonal friction within the family (Goddard et al., 2011; Grover, Williams et al., 2011; Hoyle et al., 2013; Whitney et al., 2012). However, there is insufficient evidence from RCTs to conclude that these interventions also have a positive impact on patient's outcome.

In addition, previous research from Eisler's and colleagues research group in the UK showed that family therapy was more effective than individual supportive therapy in improving psychological functioning of patients and in reducing EE in both patients and carers. Warmth between carers also increased after family therapy (Eisler, Simic, Russell, & Dare, 2007). Specifically for patients with early onset AN that presented a short illness duration, family therapy was of more benefit than individual therapy (Russell, Szmulker, Dare, & Eisler, 1987). However, family interventions in which carers are seen separately from the patients are

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recommended for families with high levels of criticism and hostility (Le Grange, Eisler, Dare, & Russell, 1992).

Overall, clinical trials involving family interventions support the idea that EE, burden and distress can be alleviated if carers are helped in their caregiving role. There is limited data available regarding the effect of family treatment on patient's outcome and about which type of treatment tends to be more effective in improving the caregiving experience. Interventions for carers can be divided into two groups: 1) guided self-help interventions in the form of workshops, telephone coaching, DVDs or websites (i.e. interventions by Grover, Williams et al., 2011; Pépin & King, 2013; Sepúlveda et al., 2010) and 2) self-help interventions via manuals, books or websites (i.e. interventions by Goddard et al., 2011; Hoyle et al., 2011), with the first group of interventions requiring more guidance and implication from the therapist. The content of each type of treatment, as well as the mechanisms that each one of them uses to bring about change, varies, with some of them offering more knowledge and understanding of the illness and others focusing more on teaching communication skills to carers. However, our understanding of the process of change leading carers to a better caregiving experience and patients to recovery is still limited and should be thoroughly investigated in the future.

### **4.8. Summary of Chapter**

EE has been extensively researched across psychiatric conditions, starting in the 60s among families of patients with schizophrenia. The relevance of EE as the strongest family predictor of illness outcome has also spawned research on its relevance in EDs. The chapter has briefly summarized the five components of EE, has then discussed its role as a key maintenance factor in EDs and has also considered gender differences between carers and illness-related characteristics. The available measures for the assessment of EE among ED populations as well as studies using them have been presented in the next section and are illustrated in Table 1 and Table 2. The chapter concludes by highlighting the need for the validation of self-report measures assessing EE among EDs carers in Spain. A valid and reliable assessment of the emotional experience at home would also permit us

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to evaluate outcomes of family-based interventions targeting carers' critical, hostile or over-controlling reactions to the illness.

## **AIMS OF THE THESIS: What we have learnt and what needs to be addressed**

The information provided in the previous chapters has advanced understanding about family caregiving in EDs, and more particularly about the vicious cycle of unhelpful interactions between family members that can worsen pathology. Thus, the family of the patient with an eating disorder has a central role in the maintenance of the illness and needs to be a focus of treatment. Many family interventions have targeted high EE levels in carers, proving their effectiveness in the improvement of the caregiving experience and of illness outcome among patients. However, there are some issues that must be addressed in future research, some of which are presented below:

First, following the interpersonal maintenance model in EDs, patients' and carers' characteristics should be attended to when evaluating the family caregiving. For example, the **impact of the changing clinical manifestations of the illness**, rather than solely its diagnosis, on carers' emotional well-being should be addressed in future research, together with interpersonal factors which have already been included in many studies, such as contact hours. In addition, the differences found between mothers and fathers in respect to their emotional response to the illness appear to support the importance of considering **a gender-specific approach** when evaluating the family strain process in EDs or when carrying out interventions that aim to reduce EE in carers. Thus, an emerging aim of this thesis is to gain a better understanding of the above-mentioned patients' and carers' features which may be associated with psychological distress among carers.

Second, one of the fundamental research objectives in clinical psychology is to gather empirical evidence on the psychometric properties of psychological assessment instruments. The review of the literature has shown that there is **an absence of self-report questionnaires validated in Spanish** to measure EE among relatives of patients with an ED. Therefore, another aim of this thesis is to meet this need. However, in order to move towards a valid and cost-effective evaluation of EE, the following two aspects should be taken into account when selecting an instrument and carrying out validation research: a) self-report instruments are more cost effective than face-to-face interviews, especially when

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considering complex clinical and research settings, b) relative's perceptions of the emotional environment at home, especially in EDs, may be more valid than those of patients.

### Specific aims

In particular, the main objective of the **Study 1** is to examine the psychometric properties of the Spanish version of the Level of Expressed Emotion scale (LEE) (Kazarian et al., 1990) among carers of patients with an ED. The specific aims of the study are: 1) to examine the structural validity of the instrument through an Exploratory Factor Analysis (EFA) and 2) to assess the internal consistency estimates of the LEE and its convergent validity with measures assessing psychological distress and burden in carers.

The main purpose of the **Study 2** is to evaluate the psychometric properties of the Spanish version of the Family Questionnaire (FQ) (Wiedemann et al., 2002) and to further examine the differences between mothers' and fathers' emotional response to an eating disorder. The specific aims of the present study are: 1) to test the validity of factor solutions proposed for the Spanish version of the FQ via Confirmatory Factor Analysis (CFA) by gender and 2) to explore internal consistency estimates of the FQ for each subscale score, as well as the convergent and concurrent validity estimates of the measure, by gender.

Finally, **Study 3** seeks to explore the differences in mental health among primary carers of ED patients with purging and non-purging behaviors and to determine predictors of psychopathological distress among carers.

### Hypothesis

For **Study 1**, it was hypothesized that the Spanish version of the LEE scale would show satisfactory psychometric properties among the Spanish sample of ED carers, comparable to the ones reported for the original version of the instrument. In addition, regarding the factor structure of the LEE, new subscale categorizations were expected for the Spanish LEE, suggesting transcultural differences in the emotional experiences of families in EDs, as mentioned by Kopelowitz et al. (2002).

For **Study 2**, we hypothesized that as with the original version of the FQ (Wiedemann et al., 2002), a two-factor structure reflecting the emotional

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overinvolvement and criticism subscales would account for the covariance among the 20 items of the questionnaire. In addition, gender differences in carers' emotional response to the illness were expected, with mothers being more emotionally overinvolved and fathers adopting a more critical response to the illness.

Finally, the hypotheses of **Study 3** were first, that primary carers of patients with purging behaviors would report a more negative caregiving experience in terms of EE, health status and ED specific impact, as compared to carers of patients with non-purging behaviors. Second, in each group of carers, different psychological factors associated with their health status were expected to be identified.



**STUDY 1**

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**THE SPANISH VALIDATION OF LEVEL OF  
EXPRESSED EMOTION FOR RELATIVES  
OF PEOPLE WITH EATING DISORDERS**

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*Sepúlveda, A. R., Anastasiadou, D., del Río, A. M., & Graell, M.  
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### Abstract<sup>1</sup>

**Background.** Expressed emotion (EE) is considered a general predictor of poor outcome across a range of conditions, including eating disorders, and is valuable in measuring the effect of family interventions. There are no self-report questionnaires validated in Spanish to measure EE among relatives of patients with a psychiatric condition. The aim of this study was to examine the psychometric properties of the Spanish version of the Level of Expressed Emotion scale (LEE) among relatives of eating disorder patients. **Method.** A cross-sectional study of 270 relatives of patients with an eating disorder was conducted to examine the factor structure, reliability and validity of the LEE scale. **Results.** Results indicated that the LEE-S (Spanish version) did not correspond to the *a priori* subscales described in the original version. The refined 45-item LEE-S scale consisted of four factors which explained 25.5% of variance in EE for relatives. Reliability was acceptable ( $\alpha$  ranged from .73 to .86). The discriminant validity of the subscales was moderately supported by correlations with psychological distress (GHQ-12;  $\rho = .34$ ) and specific caregiving experience (EDSIS;  $\rho = .39$ ). **Conclusions.** The LEE-S instrument has adequate psychometric properties and may be of value to assess families at risk of a negative emotional climate at home. **Keywords:** Level of Expressed Emotion, eating disorders, instrument validation, reliability

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<sup>1</sup> The following article was adapted to follow the *Spanish Journal of Psychology* guidelines

## **Resumen**

**Antecedentes.** La Emoción Expresada (EE) se ha considerado una variable general del mal pronóstico en una variedad de condiciones psiquiátricas, incluyendo los trastornos del comportamiento alimentario (TCA), y ha sido útil para medir su efecto en intervenciones familiares. Hasta la fecha, no existen cuestionarios autoinformados validados en castellano para medir la EE en familiares de pacientes con una enfermedad psiquiátrica. El objetivo del presente estudio fue examinar las propiedades psicométricas de la versión española de la escala del Nivel de Emoción Expresada (LEE-S) en familias de pacientes con un TCA. **Método.** Se ha llevado a cabo un estudio transversal, cuya muestra es de 270 familiares de pacientes con TCA, para examinar la estructura factorial, la fiabilidad y la validez de la escala. **Resultados.** Los resultados indicaron que la estructura factorial del LEE-S no se corresponde exactamente con las subescalas descritas a priori en la versión original. La nueva versión refinada del LEE-S es de 45 ítems y consta de cuatro factores que explicaron el 25,5% de la varianza en la EE de los familiares. La fiabilidad fue aceptable ( $\alpha$  entre .73 y .86). En cuanto a la validez discriminante, las subescalas del LEE-S correlacionaron moderadamente con el malestar psicológico (GHQ-12,  $\rho = .34$ ) y la experiencia específica del cuidado en TCA (EDSIS;  $\rho = .39$ ). **Conclusiones.** El instrumento LEE-S posee propiedades psicométricas adecuadas y puede ser útil para evaluar las familias con un riesgo de estar expuestas a un clima emocional negativo en su hogar.

**Palabras clave:** Escala del Nivel de Emoción Expresada, trastornos del comportamiento alimentario, validación y fiabilidad del instrumento

## **Introduction**

Expressed emotion (EE) has been extensively researched across psychiatric conditions as the strongest family factor that influences the course of an illness. It is considered a general predictor of poor outcome across a range of conditions, including eating disorders (ED) (Butzlaff & Hooley, 1998). Efforts to identify the relationship between vulnerable patients and the emotional climate of their home environment was first addressed in schizophrenia studies (Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976) through which relatives were found to exhibit high levels of expressed emotion. The relevance of this finding has spawned research of EE in different mental illnesses.

### **EE in relation to Eating Disorders**

A consistent body of work by Janet Treasure and colleagues (Schmidt & Treasure, 2006; Treasure et al., 2008; Treasure et al., 2007b) suggests that the type of close interpersonal interaction captured in the construct of EE as well as the reaction of family members to the illness may be causal maintaining factors in EDs. In this line, several studies that have examined the relationship between EE and patient relapse have shown that EE is a reliable predictive variable (Hodes & Le Grange, 1993; Szmukler, Eisler, Russell, & Dare, 1985; van Furth et al., 1996; van Furth, van Strien, van Son, & van Engeland, 1993). Furthermore, caregivers tend to perceive themselves to be helpless and despair at managing eating disorder behaviours (ie. food restriction or vomiting) and communicating with their relative (ie. low mood or irritable) (Graap et al., 2008; Perkins, Winn, Murray, Murphy, & Schmidt, 2004; Santonastaso, Saccon, & Favaro, 1997; Whitney et al., 2005), which in turn, can lead to conflictive situations. Overall, it seems that EE of relatives is a valid construct realm of eating disorders and can be modified through family-based interventions (Sepúlveda et al., 2009; Uehara, Kawashima, Goto, Tasaki, & Someya, 2001; van Furth et al., 1996).

### **Measuring EE**

The first instrument administered to assess the level of EE experienced by the primary relative was the Camberwell Family Interview (CFI), which required up to 5 hours to complete (Brown & Rutter, 1966) followed by a modified version that

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only required around to 2 hours (Vaughn & Leff, 1976). Researchers have found that the CFI has good validity and satisfactory reliability across cultures (Hashemi & Cochrane, 1999). However, the time-consuming administration and coding limits along with its widespread utilization has led researchers to look for an alternative. In this manner the Five-Minute Speech Scale (FMSS) (Magana et al., 1986) was developed, which is a more feasible tool, though it still requires coding by a qualified rater. Both semi-structured interviews have been used in Spain: the CFI has been validated in a Spanish population (Gutiérrez, 1986) and has been used specifically in EDs (Rodríguez & Vaz, 2005), and the FMSS (Muela & Godoy, 2010), has been validated and applied to relatives of patients with schizophrenia. Likewise, several self-report questionnaires have been developed to assess EE experienced by either relatives or patients and the exhaustive review of EE instruments by van Humbeeck, van Audenhove, De Hert, Pieters, & Storms (2002) found nine valid alternative questionnaires, which has facilitated the clinical and research utility of EE.

### **Development and course of the Level of Expressed Emotion Scale**

The Level of Expressed Emotion Scale (LEE) was developed to measure the emotional climate of the home environment, as perceived by the patient (Cole & Kazarian, 1988). The scale's 60-items generated four factor correlates of the EE construct (Vaugh & Leff, 1981): a) intrusiveness, b) emotional response to the patient's illness, c) negative attitude towards illness and d) tolerance and expectations relating to the patient. Each of these four components included 15 true-or-false questions. Scores are calculated for each scale as well as for a total score. A family member is classified as showing high EE when his or her score lies above the median. The internal consistency indices for the scales ranges from .84 to .95 (Cole & Kazarian, 1993). Moreover, the intrusiveness and tolerance/expectation scales are significantly correlated with the key relative's CFI critical comments (Kazarian, Malla, Cole, & Baker, 1990).

Furthermore, a version of the LEE scale designed for the relatives of patients was also developed by the authors (Kazarian et al., 1990) with slight modifications of the original scale (pronoun changes) but with no item reduction. In each statement, "She" was changed to "I". For example, "She says I lack control" was

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changed for “I say she lacks control”; or in another statement, “She doesn't butt into my conversations” was replaced by “I don't butt into her conversations”. Only the LEE total score and the intrusiveness scales from the relatives’ version correlated significantly with the CFI critical comments (Kazarian et al., 1990). Although the LEE relatives version has not been widely used (see Table 1), previous studies have shown satisfactory indices of internal consistency and test-retest reliability, as well as satisfactory predictive validity, for relatives of Caucasian schizophrenic patients compared with Mexican-Americans (Kopelowicz et al., 2002) and it has also been used in other psychiatric populations such as those with an obsessive-compulsive disorder (van Noppen & Steketee, 2009).

Table 1 shows psychometric properties of the patient and relative versions of the LEE scale as well as several reviews on the patient version. In fact, certain modifications and improvements have been developed using factor analysis and a four-point Likert scale in the Dutch version for patients (Gerlsma & Hale, 1997; Gerlsma, van der Lubbe, & van Nieuwenhuizen, 1992). Likewise, Startup (1999) examined the three-factor model of Gerlsma et al. (1992) using a confirmatory factor analysis in an English sample and obtained appropriate fit indices, all greater than .70 (Startup, 1999). Recently, the scale was translated into Chinese using a four-point Likert scale obtaining a four-factor structure (Chien & Chan, 2009).

### ***Insert Table 1***

There is a large body of evidence suggesting that the patient version of the LEE scale should be used instead of the CFI (van Humbeeck et al., 2002). However, there is less support for the relative version of the LEE scale, despite the fact that the relatives’ critical comments, assessed by the CFI, correlated with the relative version of the total LEE score and not with the LEE patients’ version (Kazarian et al., 1990). According to the theoretical starting point of the present study, a family focused approach may be more appropriate than a patient focused one in terms of interventions addressing EE (Vaughn et al., 1976).

## **Study 1**

One of the fundamental research objectives in clinical psychology is to gather empirical evidence on the psychometric properties of psychological assessment instruments. Therefore, the main objective of the present study was to validate the relative version of the LEE scale following international standards regarding the translation and adaptation of tests among a Spanish sample of relatives of patients with an ED. We followed the subsequent steps: a) to examine the structural validity of the instrument (exploratory factor analysis); b) to assess the internal consistency (Cronbach's alpha and intercorrelations between scales) and c) to assess the discriminant validity.

## **Method**

### **Participants**

The sample of the study was comprised of 270 relatives (63% females and 37% males) who were recruited from the Eating Disorders Service of the Hospital de Valdecilla ( $n = 53$ ), from the Hospital Infantil Universitario Niño Jesús ( $n = 146$ ) and from the Spanish Eating Disorders Carers Association (ADANER) ( $n = 71$ ). All of these family members had a relative who had been diagnosed with an eating disorder following DSM-IV criteria (American Psychiatric Association, 2002) by mental health professionals at the respective hospitals. All patients received a multidisciplinary and multicomponent treatment in specialist eating disorder units. In the case of ADANER, the association is a network of families that does not offer treatment but refers associates to appropriate specialized eating disorder units at the public hospitals. Two types of caregivers can be considered, primary caregivers who report a greater number of face-to-face hours of contact caring for the patient per week in contrast to secondary caregivers. Eighty-four secondary caregivers were included reporting on the same patient. These secondary caregivers were also included due to the significant differences between them and the primary caregivers with regard to EE levels and psychological distress (specifically in the total LEE and Intrusiveness subscale, as well as the General Health Questionnaire (GHQ-12), due to the fact that subscale scores were skewed using pairwise comparisons Wilcoxon tests).

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### **Procedure**

Participants were recruited over a period of two years. To be eligible for the study, the caregiver had to be either living with, or directly involved in the care of a person with an ED. Relatives were given an information sheet describing the study. Questionnaires were completed at the respective hospitals. The design estimated that an adequate sample size for exploratory factor analysis was close to 5 subjects per item and allowed a non-response rate of up to 5% (Costello & Osborne, 2005). We expected to collect a sample of 316 caregivers. Ethical committee approvals at the hospitals were granted for the study (Reference code, R-009/10).

Although a slightly higher response rate was expected, ultimately a total of 320 questionnaires were obtained. However, 39 (12.2%) were excluded due to incomplete data. Exclusion criteria were set at three missing responses in the LEE, the Eating Disorders Symptom Impact Scale (EDSIS) and/or the General Health Questionnaire (GHQ-12). Likewise, 11 outliers who scored zero on the GHQ-12 were also removed. A final sample of 270 relatives was included in the statistical analysis.

### **Translation and cultural validation**

The following translation and adaptation procedures were used for the LEE: (a) two independent translations of the original 60-item version with dichotomous scoring were made from English into Spanish by two expert translators, with knowledge of psychology and psychopathology; (b) comparison of the translations to assess differences in interpretation and to identify points of disagreement between them; (c) back translation into English by another expert translator; (d) comparison of the direct and back-translation versions by translator and researchers to verify the conceptual and semantic equivalence of the sentences; (e) administration of the scale to 10 caregivers from the Spanish Eating Disorders Carers Association, identifying terms subject to confusion and possible difficulties in the scale's application, f) finally, pertinent adjustments in the writing were made, considering the existing terminology in the Spanish literature on EDs and drafting the definitive version presented in this work. The translation has been approved by the questionnaire authors.



## **Assessment Measures**

**Clinical and demographic assessment:** Relatives completed a demographic questionnaire that included details about themselves (e.g. age, education level, marital status); information about patients' symptoms (e.g. subtype of disorder, duration of the illness) and aspects of caregiving experience (e.g. average of daily hours of face-to-face contact).

**Level of Expressed Emotion Scale (LEE)** (Cole & Kazarian, 1988). The LEE is a 60-item self report instrument with a true/false scale which is based on the theoretical dimensions of EE and assesses four types of perceptions that relatives or patients hold on the emotional climate of their home environment: intrusiveness, emotional response, attitude toward illness and tolerance/expectations. When administered to relatives (Healey, Tan, & Chong, 2006; Kazarian et al., 1990; Kopelowicz et al., 2002; van Noppen & Steketee, 2009) the instrument demonstrated good psychometric properties.

**General Health Questionnaire (GHQ-12)** (Goldberg & Williams, 1988). The GHQ-12 was used to measure relatives' level of psychological distress. Each item is rated on a 4-point scale (range 0–3) with scores ranging from 0-36, with higher scores indicating increased psychological distress. The GHQ has shown high internal reliability ( $\alpha = .91$ ) and high validity. The Spanish version was validated (Lobo & Muñoz, 1996) and it has been studied in general adult samples (González-Romá et al., 1991; Sanchez-Lopez & Dresch, 2008) with a satisfactory internal consistency of .76.

**Eating Disorder Symptom Impact Scale (EDSIS)** (Sepúlveda, Whitney, Hankins, & Treasure, 2008) is a 24-item scale assessing the negative appraisals on specific aspects of caregiving in EDs (nutrition, guilt, dysregulated behaviour and social isolation) using a 5-point Likert scale. Higher scores mean negative appraisals on caregiving related to the symptoms. The internal consistency is high ( $\alpha = .90$ ). It was translated into Spanish and validated in a clinical sample (Carral-Fernández, Sepúlveda, Gómez, Graell, & Treasure, 2011) with high reliability ( $\alpha = .88$ ).

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### **Statistical analysis**

In order to assess the psychometric properties of the relative version of the LEE scale, an Exploratory Factor Analysis (EFA) was performed using MPlus, given the dichotomous nature of the data (Muthen & Muthen, 2006). EFA was estimated using a robust weighted least squares estimator and oblique QUARTIMIN rotation. Parallel analyses were used in order to establish the number of dimensions needed to accurately account for the common variance among the items (Horn, 1965). Only items with factor loadings higher than .40 in any factors were considered for inclusion in the final scale. Scale reliability was assessed using Cronbach's alpha coefficient for the total scale and subscales. It suggested that a coefficient of .70 or higher could be considered "acceptable" (Nunnally & Bernstein, 1994). Item-total subscale correlations were also calculated.

Distributions of the subscales scores are reported in terms of range, means, and standard deviations. Discriminant validity was examined using cross-sectional data to examine the strength of association between subscale scores of the new scale LEE-S (Level of Expressed Emotion-Spanish version) and psychological distress (GHQ-12) as well as specific aspects of caregiving related to the symptoms (EDSIS), using Spearman correlations (non-normal distribution). The validity was also explored by examining the association between relatives' age, type of diagnosis, duration of illness, patient's symptomatology, comorbidity and the subscales and the total LEE-S score, expecting stronger correlations in younger relatives, those of patients with BN, longer duration of the illness, presenting vomiting symptoms and comorbidity. Binary variables were: type of diagnosis (anorexia/bulimia nervosa), patient's symptomatology (restricting/vomiting) and comorbidity with the following symptoms: alcohol abuse/stealing/self-harm (yes/no). Cohen (1988) suggested the following guidelines: higher than .5 is large, .49 - .3 is moderate, .29 - .1 is small.

## **Results**

### **Sample characteristics**

The mean age of the 270 relatives was 48.8 years ( $SD = 7.22$ ; range: 27 - 72). Of the 270, 186 were primary caregivers, 165 of which were females (88.7%), and 84

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were secondary caregivers, 5 (6%) of which were females. Of the sample, 86.2% relatives were married or living with a partner, 10.8% were divorced or separated and 3% were single or widowed; 65.3% of the sample was employed with a full or part time job. More than half of the sample (60.4%) was educated up to a secondary level and 39.6% was educated up to higher education. The whole patient group ( $n = 186$ ) was made up of females (100%) with a mean age of 19.7 years ( $SD = 5.7$ ; range = 12 - 34). Of the patients, 128 had a diagnosis of anorexia nervosa (70%) and 58 had bulimia nervosa (30%). The mean age of ED diagnosis was 16.5 years ( $SD = 4.3$ ) and the mean duration of their illness was 2.6 years ( $SD = 3.4$ ; range = 1 - 20). Clinical symptoms reported by the relatives were the following: 71.7% ( $n = 127$ ) restricted food intake and 28.8% ( $n = 51$ ) self-induced vomiting. Finally, 27.4% ( $n = 49$ ) of relatives reported self-harm behaviours, 15.7% ( $n = 28$ ) reported stealing and 7% ( $n = 12$ ) reported alcohol abuse. Comorbidity of two or more behaviours was present in 13.4% ( $n = 25$ ) of the patients.

### **Content Validity**

The 3 expert translators all agreed that 55 out of the 60 items on the scale were valid related to conceptual and semantic equivalence of the sentences; therefore no amendment to these 55 items was required. For the remaining 5 items, terms such as “reassure”, “flies off” and “nosing” received minor modifications for cultural relevance. The administration of the scale to 10 caregivers from the Spanish Eating Disorders Carers Association identified 2 terms subject to confusion: “nosing about my business” and “butts into my private matters”, the rest of the items were relevant and familiar.

### **Exploratory factor analysis**

Given that responses to the LEE were binary (true-or-false), EFA was performed. Results from parallel analyses showed that the best structure for this data would be four factors. The EFA revealed a four-factor structure explaining 28.5% of the total variance. At this step, 15 items (1, 5, 15, 16, 17, 18, 21, 24, 25, 29, 40, 47, 51, 57 and 60) had factor loadings smaller than .40 and therefore were excluded from further analysis. The remaining 45 items accounted for 25.5% of

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the variance. Table 2 shows the item loadings, variance explained, item-total correlations and reliabilities for the four subscales and the total LEE-S.

### ***Insert Table 2***

As Table 2 shows, most of the items removed were originally part of the Intrusiveness scale and four items were from the Attitude toward the illness scale. Factor 1 included 14 items from three different original subscales such as “I support her when she needs it” (original item from emotional response) or “I understand her limitations” (original item from tolerance/expectations) or “I don’t feel that she’s causing me many troubles” (original item from attitude toward illness). All of these items were related to denial of the illness and negative feelings about the patient, and the label of “Attitude toward illness” was maintained. Regarding Factor 2, this subscale was comprised of only 8 original items from intrusiveness, which refers to offering unsolicited and critical advice, and maintained the same label, “Intrusiveness”. Moreover, Factor 3 included 14 items from three different original subscales such as “I say she lacks control” (five items from attitude toward illness), “I get angry with her, things don’t go right” (five items from tolerance/expectations), “I blame her for things not going well” (four original items from emotional response) and this factor was labelled “Hostility toward the patient” as the content of the items was related to irritability/hostility towards the patient. Finally, Factor 4 was comprised mostly of items from the original emotional response subscale, 7 items out of 9. The content of these items were related to lack of tolerance or coping with the illness such as “I can cope well with the stress”, thus, it was labelled “Tolerance or Coping with illness”. None of the items were deleted from the original emotional response subscale and were shared between Factors 1, 3 and 4.

### **Scoring the LEE-S scale**

As a result, the final number of items in each of the four factors was either 14 (Attitude towards the illness (ATI) and Hostility (H); range = 0 - 14), 9 (Tolerance/Coping with illness (T/CI); range = 0 - 9), or 8 (Intrusiveness (I) range = 0 - 8). The scoring for the scale is 0 if True and 1 if False (range for total scale = 0 - 45). The

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following items are reversed: 3, 7, 8, 10, 13, 19, 20, 22, 26, 27, 33, 35, 36, 37, 39, 41, 42, 45, 50, 52, 54, 55, 56 and 58.

The mean of the total LEE-S scale for the 270 caregivers was 11.4 ( $SD = 6.7$ ; range = 1 - 38), and the means for the subscales were the following: Attitude toward illness was 1.3 ( $SD = 2.1$ ), Intrusiveness was 3.0 ( $SD = 2.2$ ), Hostility was 3.4 ( $SD = 2.9$ ), and finally, Tolerance/Coping with illness was 3.7 ( $SD = 2.4$ ).

### **Reliability**

Cronbach's alpha values for each of the subscales of the relative version of the LEE-S were: .79 for the Attitude toward illness subscale, .75 for the Intrusiveness subscale, .78 for the Hostility subscale and .73 for the Tolerance/Coping with illness subscale. The value for the relative version of the total LEE-S instrument was .86 (see Table 2).

### **Item-total subscale correlations and intercorrelation**

Correlational analyses between items and total subscales were conducted to measure the degree with which the items for each subscale capture specific characteristics or homogeneity as shown in the Table 2. The 45-items inter-correlated between .15 and .56, indicating that each item contributes to the measurement of the total LEE-S construct. Item-scale correlation ranged from .15 to .46 in the Attitude toward illness subscale, .20 to .39 in the Intrusiveness subscale, .28 to .56 in the Hostility toward the patient subscale, and finally, .20 to .50 in the Tolerance or Coping with illness subscale.

### **LEE-S subscale correlations**

All LEE-S subscales intercorrelated substantially between themselves and with the LEE-S total score, with significant associations ranging between .19 and .81, except the Attitude toward illness with Intrusiveness subscales. Of all the LEE-S subscales, the Hostility subscale showed the highest correlation with the LEE-S total score (Spearman's  $\rho = .81, p > .01$ ). Results are shown in Table 3.

### ***Insert Table 3***

### Discriminant Validity

Discriminant validity was determined through correlations between the four subscales scores and the total LEE-S score, and the total score of the EDSIS and its subscales and the GHQ-12 total score. The LEE-S total score was significantly and positively correlated with the total score of the EDSIS (Spearman's  $\rho = .39, p > .01$ ). All dimensions of the LEE-S were related to EDSIS subscales and GHQ-12 scale, except the Attitude toward illness subscale that did not correlate with either EDSIS or GHQ-12 total scores. Regarding EDSIS subscales, the highest correlation was between Dysregulated Behaviour and the LEE-S total score (Spearman's  $\rho = .42, p > .01$ ). Results are also illustrated in Table 3.

### Clinical and demographic variables and the LEE-S

Negative and low correlations were found only between relative's age and Intrusiveness (Spearman's  $\rho = -.13, p < .05$ ) and the Tolerance/Coping with the illness subscale (Spearman's  $\rho = -.13, p < .05$ ), which means higher levels of intrusiveness and lack of coping when parents are younger. There were also significant differences in the Attitude toward illness subscale between patients with AN and BN, with the latter scoring higher in the subscale (Spearman's  $\rho = .18, p < .01$ ). There were no significant associations between illness duration and the LEE-S subscales ( $p > .05$ ) nor with patient's symptomatology ( $p > .05$ ). Finally, there was no association between comorbidity with alcohol abuse/stealing/self-harm and the LEE-S subscales ( $p > .05$ ).

### Discussion

The study has verified that the relative version of the LEE-S is a valid and reliable instrument to measure the level of expressed emotion presented by a relative of a person with an eating disorder. As far as we know, it is the first self-report measure validated in Spanish that makes it possible to assess EE from the relative's perspective. Moreover, "LEE is a more readily applicable instrument, convenient to administer, in contemporary family settings" compared with other self-report questionnaires (Chien & Chan, 2010). The content of the items was built upon empirical findings and based on the model provided by Vaughn and Leff (1981). A review of the literature has shown several modifications of the first

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version of the LEE scale which assesses patient's perception of EE (Cole & Kazarian, 1988) and its psychometric properties. However, the relative version of the LEE, provided by Kazarian et al. (1990) has been selected as it fits our conceptualisation of EE from the relative's point of view.

Regarding the instrument's content validity, all items of the Spanish scale were considered appropriately translated and with high semantic equivalence, with only five items requiring minor amendments.

The 4-factor structure of the Spanish relative version of the LEE, with a dichotomous format, is consistent with the multidimensional nature of the original version proposed by Cole and Kazarian (1988), which supports the assumption that the multidimensional nature of the emotional climate for relatives of patients with schizophrenia, also extends to other psychiatric conditions. The solution of four factors seemed to best fit the data, with consistent high factor loadings for each of the four factors (41-98), accounting for an acceptable percentage of the variance (25.5%). However, the Spanish version has been shortened to 45-items, as some of the items did not contribute sufficiently to the total scale. Differences in the item-subscale categorization may be grounded in different cultural values and beliefs related to relatives' perceptions of EE as well as the younger age of our sample and the consequent shorter illness duration of patients ( $M = 4.8$  years) compared to other studies using the relative version of the LEE scale (Hearley et al., 2006; Kazarian et al., 1990; Kopelowicz et al., 2002).

Most of the items were removed from the Intrusiveness subscale (for example, items 1, 5, 17, 21, 25, 29, 57) suggesting that repeated attempts to establish contact or to offer unsolicited help is probably considered to be a normal and supportive position for parents. However, Factor 2 maintained the original items of the Intrusiveness subscale. Regarding Factor 4, which was comprised of 9 items, 7 items were taken from the original emotional response subscale. In addition, we have changed two labels in the four-factor solution; Factor 3 which was labelled "Hostility" because the content of the items were related to hostility towards the patient, and Factor 4 which was labelled as "Tolerance/Coping with the illness", because the content was related to the method of coping with the illness.

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Analysis of the internal consistency demonstrated high homogeneity between items and for the 4-factor solution (labelled as Attitude toward illness, Intrusiveness, Hostility toward patient and Tolerance/Coping with the illness) with acceptable values of internal consistency between .73 to .79 for the four subscales and .86 for the total LEE-S scale. Regarding intercorrelations between LEE-S subscales, all subscales were positively and moderately intercorrelated as expected, except for Intrusiveness and Attitude towards the illness, which did not intercorrelate significantly. However, our results cannot be compared with others, due to limited research provided from studies using the LEE-relative version.

With respect to discriminant validity, we found moderate correlations between scores on the LEE-S scale and the specific ED caregiving experience (EDSIS) as well as psychological distress (GHQ-12), which suggests that EE evaluated with a self-report instrument and from a relative's perspective is a relevant construct that may have prognostic significance in family-based interventions, as also shown with the FMSS (Sepúlveda et al., 2009; Uehara et al., 2001) and the CFI (van Furth et al., 1996). More particularly, of all the negative and specific appraisals of caregiving (EDSIS subscales), Dysregulated Behaviour related to the illness was the aspect that most correlated with the total LEE-S scale ( $\rho = .42$ ); this might explain how "abnormal" ED behaviours arouse high levels of EE in relatives, or on the contrary, as the direction of the correlation has not been studied, how high EE as a maintaining factor, may negatively affect the ED, increasing dysregulated behaviours in patients. Furthermore, Hostility towards the patient was the subscale that most strongly related to specific aspects of caregiving of the total EDSIS ( $\rho = .36$ ). Again, the direction of correlation is not known; hostility manifested by the patient may increase specific ED burden in the relative or *vice versa*, when burden of caregiving is high, high levels of hostility are expected by the patient.

Regarding clinical and demographic variables and the LEE-S associations, we found that younger relatives lack coping strategies and tend to be intrusive toward the ailing family member in contrast to results found by Sepúlveda et al. (2009) where no association between age and EE levels was found using the FMSS. We also found a more negative attitude toward illness in relatives of patients with BN,



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compared to patients with AN. In contrast, Santanastaso et al. (1997) found that over-involvement was higher for AN relatives compared with BN relatives, and in the study by Graap et al. (2008), in which relatives of patients with BN reported a lower number of problems, less need for interventions, less burden and fewer health problems, as compared to relatives of patients with AN and schizophrenia. Finally, EE in our study was present during the whole course of the illness without significant changes regarding the illness duration, which suggests the necessity for family interventions at any point during the illness. On the contrary, a positive association between illness duration and EE levels was shown in the study by Sepúlveda and colleagues (2009).

There are some limitations that should be noted. Firstly, additional attention should be given to assessing test-retest reliability, a property that was not assessed in the current paper. Secondly, whether or not the scale is able to predict symptomatic improvement in ED patients and relatives after treatment requires further investigation. A third limitation is that characteristics of the illness were collected from a self-report survey completed by relatives as opposed to using diagnostic or standardized measures. Fourth, relatives were recruited from two hospitals and a caregiver organization and the generalizability of these results is uncertain. The majority of diagnoses and clinical variables (i.e. age of onset) were established by medical reports thus limiting a potential bias related to these findings to the ADANER sample. However, all of the ADANER members had been diagnosed and had received treatment (or were receiving) for their relative's eating disorder. Finally, it would be interesting to employ a confirmatory factor analysis to confirm the dimensions of the LEE-S in the Spanish sample.

In conclusion, the relative version of the LEE-S instrument showed a moderate to strong construct validity between items, internal consistency, as well as moderate discriminant validity with other instruments. The four key components of the LEE-S proposed in the present study, are widely recognized behaviours and emotional styles which conceptualize EE construct in EDs (Schmidt & Treasure, 2006; Treasure et al., 2008). Several family-based interventions have addressed these four components so as to improve the caregiving experience and illness outcome (Uehara et al., 2001). Consequently, we suggest the further use of the

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relative version of the LEE-S in clinical settings, although future research in this area should focus on determining a reliable cut-off point for the questionnaire and on promoting its use in other clinical populations.

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**Table 1.** Summary of relative and patient version of the LEE scale and its psychometric properties

LEE families	N	Age	Items	Scales	Coefficients	Validity	Mean scores	Comments
<i>Kazarian et al. (1990):</i> Relation between LEE, CFI and IRQ scores (unpublished)	23 relatives of schizop. patients	NS	True/False Responses			LEE Attitude Toward illness with: -CFI Critical Comments: = .49 -CFI Warmth: = -.41 LEE Total with: -CFI Critical Comments: = .38		
<i>Kopelowicz et al. (2002):</i> Comparison of Caucasians and Mexican-Americans using LEE scale (version for patients and parents)	Caucasians with schizop. & key relative: <i>N</i> = 17 Mexican Americans with schizop. & key relative: <i>N</i> = 44	Patients 35.7 y. Relatives 55.5 y.	60 items True/False Responses	1) Criticism 2) Hostility 3) Overinvolvement 4) Tolerance		<u>Predictive validity:</u> High EE predicted relapse in schizophrenia for Caucasians but not for Mexican-Americans		-No significant differences between Caucasian and Mexican patients and their families in the LEE scale -Caucasians were more often rated as high EE
<i>Healey, Tan and Chong (2006):</i> Cross-cultural validation of EE in families of psychotic patients in Singapore: a qualitative study	10 pairs of psychotic patients and caregivers	-Patients in the high EE group: 30.4 y. -Patients in the low EE group: 28.2 y.	Interviews: Discussion based on LEE scale (60 items, 4 subscales, True/False Responses)	1)Overinvolvement/ Intrusiveness 2) Criticism 3) Irritability 4) Lack of Emotional Support/Intrusiveness				-Further work on the LEE to make it appropriate for use in Singapore -Practical rather than emotional support is discussed
<i>Van Noppen and Steketee (2009):</i> To build a model of family influences on OCD symptoms	50 patients with OCD and their 50 relatives	-Patients 42 y. -Relative 46 y.	LEE's patient and relative version: 60 items True/False Responses	1) Intrusiveness 2) Emotional response 3) Attitude toward illness or upset 4) Tolerance/ expectation		Relative EE (LEE, IRQ, PRS, RRQ) after a principal component analyses: Criticism: <i>M</i> = 27.48; <i>SD</i> = 9.53; $\alpha$ = .87 Hostility: <i>M</i> = 27.50; <i>SD</i> = 23.76; $\alpha$ = .93 EOI: <i>M</i> = 20.82; <i>SD</i> = 19.08; $\alpha$ = .88		-Other instruments used to assess EE in relatives: IRQ, PRS, RRQ -The 4 measures employed (LEE, IRQ, PRS, RRQ) may prove to be a cost-effective alternative to the labor intensive CFI

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LEE patients	N	Age	Items	Scales	Coefficients	Validity	Mean scores	Comments
<i>Cole and Kazarian (1988)</i>	-103 pilot sample, psychology students, & their relatives	NS	60 items True/False Responses	1) Intrusiveness 2) Emotional response 3) Attitude toward illness or upset 4) Tolerance/ expectation	<u>Subscales:</u> = .83-.90 <u>Total:</u> = .95			
	-36 outpatients & 10 schizop. patients	35.7 y., (SD = 10.4 R = 21-64).	60 items True/False Responses	1) Intrusiveness 2) Emotional response 3) Attitude toward illness or upset 4) Tolerance/ expectation	<u>Subscales:</u> = .84-89 <u>Total:</u> = .95	With IRQ overall scales: $r(45) = .86$ With IRQ subscales: $r = .39-.96$	<u>By sex:</u> no significant differences <u>By contact time:</u> no significant differences	
<i>Kazarian et al. (1990):</i> Relation between LEE, CFI and IRQ scores	15 patients with schizop.	29.4 y.	60 items, True/False responses	1) Intrusiveness 2) Emotional response 3) Attitude toward illness or upset 4) Tolerance/ expectation		LEE Intrusiveness with: -CFI Critical Comments: = .40 LEE Expectations with: -CFI Critical Comments: = .40		
<i>Gerlsma et al. (1992):</i> factor structure of the Dutch version of LEE	345 persons from the general community	46 y. SD = 15.8	33 items, four-point LS	1) Lack of emotional support 2) Intrusiveness/ Control 3) Irritability 4) (Total score) <u>Variance explained:</u> 1) 26.2%; 2) 9.7%; 3) 6.1%	<u>Subscales:</u> = .79-81		<u>By sex:</u> males more intrusiveness than females ( $t(313) = 4.13$ , $p < .001$ ) <u>By contact time:</u> Correlated significantly with intrusiveness ( $r = 0.26$ )	
<i>Cole and Kazarian (1993):</i> Predictive validity of LEE. Readmission follow up data for 1, 2 and 5 year periods	<u>1988 sample:</u> 35 outpatients & 11 inpatients with schizop. <u>Follow up:</u> Readmitted & non readmitted	35.7 y., (SD = 10.4 R = 21-64).	60 items True/False Responses	1) Intrusiveness 2) Emotional response 3) Attitude toward illness or upset 4) Tolerance/ expectation				-A clear trend of higher rehospitalization rate for the high LEE group (LEE score > 9) across all three follow-up periods -The cut-off point proposed in the study requires replication and validation with other clinical groups

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<i>Gerlsma and Hale (1997):</i> Predictive power and construct validity of LEE	-c.s.:26 depressed outpatients and their 26 partners -h.s.:40 couples from general community	42 y.  32 y.	38 items, four-point LS	1) Lack of emotional support 2) Irritability 3) Intrusiveness/control 4) (Total score) <i>New item added</i> 5) Criticism (5 items)	1) $\alpha = .92$ c.s. $\alpha = .86$ h.s. 2) $\alpha = .88$ c.s. $\alpha = .82$ h.s. 3) $\alpha = .84$ c.s. $\alpha = .82$ h.s. 4) $\alpha = .93$ c.s. $\alpha = .90$ h.s. 5) $\alpha = .72$ c.s. $\alpha = .65$ h.s.	Partner's BDI depression with patient's LEE Intrusiveness ( $r = .46$ )	-c.s.: $d = 0.41$ in intrusiveness & smaller scores in the other subscales ( $d < = 0.23$ ) -h.s.: $d = 0.46$ in lack of support $d = 0.53$ in intrusiveness $d = 1.45$ in irritability & $d = 0.83$ in total score	
<i>Startup (1999):</i> Confirmatory factor analysis of LEE (Gerlsma's 33 item scale)	-75 volunteers -Follow up (2 months later): 55 of 75 volunteers	43.2 y.	33 items, four-point LS	1) Lack of emotional support 2) Intrusiveness/Control 3) Irritability 4) (Total score)	1) $\alpha = .88$ 2) $\alpha = .83$ 3) $\alpha = .84$ 4) $\alpha = .92$	Retest reliability ( $N = 75$ & $N = 55$ ): 1) .74 2) .78 3) .75 4) .83	1) $M = 1.63$ ; $SD = 0.49$ 2) $M = 1.68$ ; $SD = 0.62$ 3) $M = 1.81$ ; $SD = 0.67$ 4) $M = 1.69$ ; $SD = 0.47$	-Congruence between rotated and target components were: 1) lack of emotional support: .80 2) intrusiveness: .84 3) irritability: .84 -Reassignment of some items to different scales -Add subscale for criticism
Hale, Raaijmakers, Gerlsma and Meeus (2007): Confirmatory factor analyses to examine if LEE had the same four-factor structure for adolescents as it does for adults	-311 adolescents	13.2 y.	38 items, four-point LS	1) Lack of emotional support 2) Intrusiveness 3) Irritability 4) Criticism	1) $\alpha = .88$ 2) $\alpha = .83$ 3) $\alpha = .82$ 4) $\alpha = .73$ Total = .93	LEE scores total and subscales with: -CDI Depression: = .16-.34 -SCARED Anxiety: = .17-.26	The four-factor model showed a better fit than the one-factor model ( $D\chi^2$ (6) = 643.5)	
<i>Chien and Chan (2009):</i> Psychometric properties of Chinese version of LEE scale	321 outpatients with schizoph.	27.1 y.	Refined Chinese version: 52 items, four-point LS	1) Intrusiveness 2) Attitude toward illness 3) Expectations of the patient 4) Degree of emotional involvement	<u>Total</u> : = .88 <u>Subscales</u> : = .80-.90	-With FAD total and subscales: = -.30 & -.70 -With SLOF: = -.42 & -.53		
<i>Chien and Chan (2010):</i> Further validation of Chinese version of LEE scale: 6 months follow-up	405 outpatients with psychotic disorders	24.1 y.	Chinese version of LEE with 52 items, four-point LS	1) Intrusiveness 2) Attitude toward illness 3) Expectations of the patient 4) Degree of emotional involvement Variance explained:70%	<u>Total</u> : = .88 <u>Subscales</u> : = .82-.92	-Construct validity between items: = .41 -.70 -Intra-class correlation coefficients of the LEE scores between the two measurements: = .88 -With FAD total and subscales: = -.31 & -.69 -With SLOF: = -.40 & -.54	1) $M = 8.73$ ; $SD = 1.51$ 2) $M = 6.51$ ; $SD = 1.41$ 3) $M = 7.61$ ; $SD = 1.32$ 4) $M = 6.01$ ; $SD = 1.21$ 5) Total Mean = 27.02; $SD = 5.56$	

## ***Study 1***

**Note:** c.s.=control sample, h.s.=healthy sample, LS=likert scale, schizoph.=schizophrenia, OCD=Obsessive Compulsive Disorder, M=Mean, ns=not significant, SD=Standard Deviation, R=Range, NS=Not Specified, y.=years. LEE= Level of Expressed Emotion (Cole and Kazarian, 1993); IRQ=Influential Relationships Questionnaire (Cole & Kazarian, 1988); PRS=Patient Rejection Scale (Kreisman, Simmens, & Joy, 1979); RRQ=Relative's Reaction Questionnaire (Chambless et al., 1999); CFI=Camberwell Family Interview (Vaughn & Leff, 1976); SLOF=Specific Levels Of Functioning (Schneider & Struening, 1983); FAD=McMaster Family Assessment Device (Epstein et al., 1983); BDI=Beck Depression Inventory (Beck, 1996); CDI=Child Depression Inventory (Kovacs,1983); SCARED=Screen for Child Anxiety Related Emotional Disorders (Birmaher et al., 1997)

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**Table 2.** Factor matrix following exploratory factor analysis for LEE scale (original numbers of the items were kept)

		Factor Loadings				Item-scale correlation
Item (Cronbach alpha 0.86)	Original LEE	1	2	3	4	
Factor 1: Attitude toward illness (14 items, Cronbach alpha 0.79)						
LEE-44: I support him/her when he/she needs it. Cuenta con mi apoyo cuando lo necesita (33)*	T/E	0.98				0.34
LEE-31: I try to make him/her feel better when he/she is upset or ill. Intento que se sienta mejor cuando está disgustado/a o enfermo/a (21)*	ATI	0.91				0.28
LEE-23: I make him/her feel valuable as a person. Le/la hago sentirse valioso/a como persona (16)*	ATI	0.85				0.39
LEE-59: I try to reassure him/her when he/she is not feeling well. Intento tranquilizarle/la cuando no se encuentra bien (45)*	ATI	0.73				0.25
LEE-19: I don't help him/her when he or she is upset or feeling unwell. No le/la ayudo cuando está disgustado/a o no se encuentra bien (13)*	ATI	0.70				0.22
LEE-11: I am sympathetic towards him/her when he/she is not feeling well Soy comprensivo con él/ella cuando no se encuentra bien (9)*	ATI	0.67				0.31
LEE-43: When he/she is upset, I am a considerate person. Soy una persona considerada cuando está disgustado/a (32)*	ATI	0.62				0.32
LEE-34: I hear her/him out. Escucho todo lo que me tiene que decir (24)*	ER	0.62				0.26
LEE-42: I get angry with her/him for no reason. Me enfado con él/ella sin motivo (31)*	ER	0.57				0.34
LEE-48: I am understanding if he/she makes a mistake. Soy comprensivo/a si comete un fallo (36)*	T/E	0.55				0.37
LEE-32: I am realistic about what he/she can and cannot do. Soy realista acerca de lo que puede hacer y de lo que no puede hacer (22)*	T/E	0.55				0.46
LEE-28: I understand his/her limitations. Comprendo sus limitaciones (19)*	T/E	0.51				0.32
LEE-35: I say it is not OKAY to seek professional help. Expreso que no está bien buscar ayuda profesional (25)*	ATI	0.48				0.15
LEE-2: I calm him/her down when he/she is upset Cuando está molesto/a le/la calmo (1)*	ER	0.43				0.26

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### Factor 2: Intrusiveness

(8 items, Cronbach alpha 0.75)

LEE-45: I butt into his/her private matters. Me intrometo en sus asuntos privados (34)*	(I)	0.81	0.37
LEE-33: I am always nosing about into his/her business. Estoy siempre husmeando en sus asuntos (23)*	(I)	0.78	0.37
LEE-53: I don't ask a lot of personal questions. No hago muchas preguntas personales (40)*	(I)	0.73	0.23
LEE-49: I don't pry into his/her life. No hurgo en su vida (37)*	(I)	0.73	0.39
LEE-37: I always have to know everything about him/her. Tengo que saberlo todo acerca de lo que hace o le pasa (27)*	(I)	0.68	0.28
LEE-41: I insist on knowing where he/she is going. Insisto en saber dónde va (30)*	(I)	0.55	0.22
LEE-13: I am always interfering Siempre estoy intrometiéndome (11)*	(I)	0.48	0.44
LEE-9: I am not over protective with him/her. No me considero demasiado protector con ella/él (7)*	(I)	0.44	0.20

### Factor 3: Hostility toward the patient

(14 items, Cronbach alpha 0.78)

LEE-8: I make him/her feel guilty for not meeting my expectations. Le/la hago sentirse culpable por no cumplir mis expectativas (6)*	(T/E)	0.72	0.35
LEE-22: I blame him/her for things not going well. Le/la culpo por las cosas que no van bien (15)*	(ER)	0.70	0.33
LEE-20: I put him/her down if she/he doesn't live up to my expectations. Le/la critico si no cumple mis expectativas (14)*	(T/E)	0.72	0.35
LEE-55: I often accuse him/her of making things up when he/she is not feeling well. Le/la acuso a menudo de inventarse cosas cuando no se encuentra bien (42)*	(ATI)	0.65	0.38
LEE-56: I 'fly off the handle' when he/she doesn't do something well. "Pierdo los estribos" cuando no hace algo bien (43)*	(T/E)	0.64	0.56
LEE-7: I say he/she just wants attention when he/she is not well. Le/la digo que sólo quiere atención cuando no se encuentra bien (5)*	(ATI)	0.63	0.31
LEE-36: I get angry with him/her when things don't go right. Me enfado con ella/él cuando las cosas no van bien (26)*	(T/E)	0.62	0.44
LEE-3: I say he/she lacks control Le/la digo que no tiene control sobre sí misma/o (2)*	(ATI)	0.57	0.30
LEE-39: I accuse him/her of exaggerating when he/she says that she is unwell. Le/la acuso de estar exagerando cuando se	(ATI)	0.54	0.30

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encuentra mal (29)* LEE-27: I say he/she causes his/her troubles to occur in order to get back at me. Le/la digo que él/ella crea estos problemas para vengarse de mí (18)*	(ATI)	0.46	0.28		
LEE-54: I make matters worse when things aren't going well. Hago que las cosas empeoren cuando no van bien (41)*	(ER)	0.46	0.42		
LEE-52: I expect too much from him/her. Tengo expectativas demasiado altas para ella/él (39)*	(T/E)	0.44	0.20		
LEE-58: I get irritated when things don't go right. Me desespero cuando las cosas no van bien (44)*	(ER)	0.44	0.48		
LEE-50: I an impatient with him/her when he/she is not well. Me vuelvo impaciente con él/ella cuando se encuentra mal (38)*	(ER)	0.41	0.47		
<i>Factor 4: Tolerance or Coping with illness</i> <i>(9 items-Cronbach alpha 0.73)</i>					
LEE-14: I don't panic when things start going wrong No pierdo el control cuando las cosas empiezan a ir mal (12)*	(ER)	0.67	0.40		
LEE-6: I don't make him/her nervous. No le/la pongo nerviosa/o (4)*	(ER)	0.62	0.31		
LEE-38: I make him/her feel relaxed when I am around. Mi presencia le/la relaja (28)*	(ER)	0.61	0.40		
LEE-30: I am able to be in control in stressful situations. Puedo mantener el control en situaciones estresantes (20)*	(ER)	0.59	0.34		
LEE-4: I am tolerant with him/her even when he/she doesn't meet my expectations. Soy comprensivo/a con él/ella incluso cuando no cumple mis expectativas (3)*	(T/E)	0.58	0.50		
LEE-26: I don't know how to handle his/her feelings when he/she is not feeling well. No sé cómo manejar sus sentimientos cuando no se encuentra bien (17)*	(ER)	0.54	0.20		
LEE-46: I can cope well with stress. Puedo manejar bien el estrés (35)*	(ER)	0.54	0.30		
LEE-10: I lose control of my temper Me enfado perdiendo los estribos (8)*	(ER)	0.51	0.47		
LEE-12: I can see his/her point of view. Puedo ver su punto de vista (10)*	(T/E)	0.47	0.27		
Percentage Variance explained (Total = 25.5)	13.5	5.4	3.5	3.2	-

Note. Bold values show on-factor loadings.

Note: Factor loadings  $\geq .40$  are reported.

In the Original version of Kazarian et al. (1990), Factor 1: Intrusiveness (I); Factor 2: Emotional Response (ER); Factor 3: Attitude towards the Illness (ATI); and Factor 4: Tolerance/expectation (T/E).

\* Numbers in the parentheses represent the item sequence in the Spanish version.

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**Table 3.** Correlations between the four subscales scores and the total score of LEE and, the four subscales scores and total score of EDSIS and the GHQ total score (N = 270)

ED subscales	Intrus.	Hostil.	Tolerance/ Coping	LEE Total	Nutrit.	Dysreg.	Guilt	Isolation	EDSIS	GHQ-12
									<b>Total</b>	
<i>N. Attitude toward illness</i>	0.04	0.29**	0.39**	0.50**	0.030	0.19**	0.08	0.01	0.10	0.09
<i>Intrusiveness</i>	-	0.31**	0.19**	0.56**	0.22**	0.17**	0.23**	0.21**	26**	0.29**
<i>Hostility toward patient</i>	-	-	0.48**	0.81**	0.26**	0.39**	0.32**	0.18**	0.36**	0.25**
<i>Lack of Tolerance/ Coping with illness</i>	-	-	-	0.77**	0.19**	0.35**	0.24**	0.07	0.28**	0.30**
<i>LEE Total</i>	-	-	-	-	0.27**	0.42**	0.34**	0.18**	0.39**	0.34**

Note. \*\* Correlation is significant at the .01 level (2-tailed)

\* Correlation is significant at the .05 level (2-tailed)



**STUDY 2**

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**SPANISH VALIDATION OF THE FAMILY  
QUESTIONNAIRE (FQ) IN FAMILIES OF  
PATIENTS WITH AN EATING DISORDER:  
DIFFERENCES IN EXPRESSED EMOTION BY  
GENDER**

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*Sepúlveda, A. R., Anastasiadou, D., Rodríguez, L., Almendros, C., Andrés, P., Vaz, F., & Graell, M.  
Psicothema, in press*

**Abstract<sup>2</sup>**

**Background.** The objective of this study is to evaluate the psychometric properties of the Spanish version of the Family Questionnaire (FQ) and to further examine the differences between mothers' and fathers' emotional response to an eating disorder (ED). **Method.** A total of 382 carers of patients with an ED participated in the study, with ages ranging from forty to fifty-three years old. **Results.** The use of confirmatory factor analysis according to gender supported both factor models of the FQ, with only minor differences in comparison to the original study performed in 2002 by Wiedemann and colleagues. The internal consistency of the Spanish version of the FQ was good. Mothers displayed significantly higher levels of emotional overinvolvement than fathers, while gender differences in critical comments were nonsignificant. The correlation of the two subscales of the FQ with a conceptually related measure (Expressed Emotion) and two unrelated ones (negative caregiving experience, distress) supports the convergent and concurrent validity of the instrument in both samples. **Conclusions.** The FQ has adequate psychometric properties and may be of value in assessing the impact of ED symptoms on the family environment. Finally, interventions that aim to reduce Expressed Emotion in carers may consider a gender-specific approach.

**Keywords:** Eating Disorders; Expressed Emotion; Family Questionnaire; validation; gender; confirmatory factor analysis

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<sup>2</sup>The following article was adapted to follow the *Psicothema* guidelines

## **Resumen**

**Antecedentes.** El objetivo del estudio es evaluar las propiedades psicométricas de la versión española del Family Questionnaire (FQ) y examinar diferencias en la respuesta emocional de madres y padres ante un trastorno de la conducta alimentaria (TCA).

**Método.** 382 cuidadores de pacientes con un TCA participaron en el estudio, con edades comprendidas entre 40 y 53 años. **Resultados.** Los resultados del análisis factorial confirmatorio según género apoyaron ambas estructuras factoriales del FQ, con solo pequeñas diferencias con el trabajo original realizado en 2002 por Wiedemann y colaboradores. La versión española del FQ presentó buena consistencia interna. Las madres puntuaron significativamente más alto en sobreimplicación emocional que los padres, mientras que las diferencias de género en comentarios críticos no eran significativas. La correlación de las subescalas del FQ con una medida conceptualmente equivalente (Emoción Expresada) y dos medidas no equivalentes (experiencia negativa del cuidador, ansiedad) apoyaron la validez convergente y concurrente del instrumento para ambas muestras. **Conclusiones.** El FQ tiene adecuadas propiedades psicométricas y puede ser útil para evaluar el impacto de los síntomas del TCA en el entorno familiar. Sería recomendable que las intervenciones familiares destinadas a reducir los niveles de Emoción Expresada tuvieran en cuenta una perspectiva de género.

**Palabras clave:** Trastornos de la conducta alimentaria; Emoción Expresada; Family Questionnaire; validación; género; análisis factorial confirmatorio

## **Introduction**

A substantial body of research has been carried out to investigate the construct of Expressed Emotion (EE) (Brown & Rutter, 1966) as the emotional experience of caring for a family member with a mental disorder and it has been found to be a significant predictor of illness outcome across a variety of psychiatric disorders (Butzlaff & Hooley, 1998; Wearden, Terrier, Barrowclough, Zastowny, & Rahill, 1998). In samples of patients with an eating disorder (ED), high levels of criticism among family members were considered to be maintaining factors of psychopathology in patients and were associated both with early dropout of patients from treatment (Szmukler, Eisler, Russell, & Dare, 1985) and with worse clinical outcomes (Uehara, Kawashima, Goto, Tasaki, & Someya, 2001).

Carers of relatives with EDs are faced with the acute negative symptoms of the illness and tend to spend a large number of face-to-face hours with the patient, supervising his/her eating habits and medical health status. Additionally, high levels of EE in carers are associated with increased psychological distress, psychological morbidity, and a negative caregiving experience (Kyriacou, Treasure, & Schmidt, 2008; Wearden et al., 1998).

However, EE levels and the resulting interpersonal friction within the family may gradually decrease, thereby improving the situation, through psychoeducational interventions (Goddard et al., 2011; Sepúlveda et al., 2010; Uehara et al., 2001). Also, psychological variables associated with carers' emotional well-being are differentiated by caregiver type; that is, primary caregivers, usually mothers, are more likely to experience negative consequences, in terms of their coping response to the illness and health status, than fathers (Sepúlveda et al., 2012).

The first instrument to reliably measure the EE construct was the Camberwell Family Interview (Brown & Rutter, 1966). Since its publication, a number of alternative methods have been developed, which are less time-consuming and present fewer coding limitations. Amongst these, the Standardized Clinical Family Interview (Kinston & Loader, 1984), and the Five Minutes Speech Scale (Magaña et al., 1986) are worth mentioning, as well as self-report instruments, such as the Level of Expressed Emotion (LEE; Cole & Kazarian, 1988).

However, there are only a few tools assessing EE in relatives that have been translated into Spanish and used by the Spanish population. In terms of interviews, the

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Camberwell Family Interview (Gutiérrez, 1986) and the Five Minutes Speech Scale (Muela & Godoy, 2010) have been adapted for use in clinical samples in Spain. With regards to self-report instruments, the LEE has been validated in a Spanish sample of relatives of patients with an ED, showing adequate psychometric properties (Sepúlveda, Anastasiadou, del Rio, & Graell, 2012).

The Family Questionnaire (FQ) was developed by Wiedemann, Rayki, Feistein, & Hahlweg (2002) as a more cost-effective and research-applicable method for assessing EE, compared to the Camberwell Family Interview (Duclos, Vibert, Mattar, & Godart, 2012). It was validated in a sample of 79 relatives of patients with schizophrenia. The instrument consists of 20 items and has a clear two-factor structure: a Critical Comments scale (CC) explaining 33.7% of variance, and an Emotional Overinvolvement scale (EOI) explaining 15% of the variance. The instrument has shown good internal consistency of .80 for the EOI scale and .92 for the CC scale. The FQ also predicts the ratings of the Camberwell Family Interview better than any other short EE instrument. Regarding the cut-off points proposed for each scale (23 for CC and 27 for EOI), the FQ presents similar levels of accuracy in identifying high EE levels as the Five Minutes Speech Scale, while at the same time it is a more cost-effective instrument than the latter (Leeb et al., 1991; Magaña et al., 1986). The measure has also been considered to be preferable to the Five Minutes Speech Scale as the latter has been found to under assess high EE in relatives (Möller-Leimkühler, 2005). Finally, gender differences in EE using the FQ have been found, with higher scores for EOI and CC among mothers compared with fathers (Kyriacou et al., 2008).

The specific aims of the present study are as follows: a) to test the validity of factor solutions proposed for the Spanish version of the FQ via confirmatory factor analysis by gender and b) to explore internal consistency estimates of the FQ for each subscale score, as well as the convergent and concurrent validity with established measures assessing EE, and other constructs related to psychological well-being.

## **Method**

### **Participants**

The participants were 382 carers of patients with an ED that were recruited for the study from the Eating Disorders Service of Hospital of Badajoz, Spain ( $N = 108$ ) and the Niño Jesus University Hospital, Madrid, Spain ( $N = 274$ ). The distribution by gender for

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the whole sample amounted to 203 mothers (53.1%) and 179 fathers (46.9%), with an average age of 46.2 years ( $SD = 5.1$ ) and 48.7 years ( $SD = 5.55$ ), respectively, and with the age of the entire sample ranging from 40 to 53 years old. Regarding their educational level, a third of the mothers (33.4%) and fathers (39.5%) reported that their highest level was university or postgraduate education. In terms of their employment status, the majority of the mothers (60.2%) and fathers (81.5%) had a full time job. Additionally, 84% of the mothers and 88.7% of the fathers were married or were living together as a couple, with 86.2% of the mothers and 58.9% of the fathers spending more than 21 contact hours per week with the patient. The 203 patients had a mean age of 15.8 years ( $SD = 3.41$ ) and a mean illness duration of 15.9 months ( $SD = 18.45$ ). The mean Body Mass Index of the patients was  $17.5 \text{ kg/m}^2$  ( $SD = 3.1$ ), and they had been diagnosed with an ED by a standard clinical interview following DSM-IV-R criteria (American Psychiatric Association, 2002) at their respective hospitals. Accordingly, 71.0% of patients had a diagnosis of anorexia nervosa, 7.5% presented bulimia nervosa, and 21.5% were diagnosed with an Eating Disorder Not Otherwise Specified (EDNOS).

## Instruments

**Sociodemographic and Clinical Questions.** Carers completed a questionnaire concerning their gender, age, educational level, marital status, employment status, and amount of contact hours per week with the patient. Patients' clinical variables were obtained through their medical records and information about their gender, age, disorder subtype, duration of the illness, weight, and height were collected. The Body Mass Index was also calculated for each patient.

**Family Questionnaire (FQ)** (Wiedemann et al., 2002). The FQ consists of 20 items, which measure EE (10 for CC and 10 for EOI). The scoring of each item ranges from 1, for 'never/rarely' to 4, for 'very often'. Higher total scores on each subscale indicate higher EE.

**Symptom Check-List-90 Revised (SCL-90-R)** (Derogatis & Melisaratos, 1983). The SCL-90 is comprised of 90 items organized within 9 symptom dimensions using Likert scoring on a scale of 1 to 4. The Global Severity Index (GSI) was taken as a global indicator of distress. The GSI is the average score of the 90 items, and is one of the most widely used indexes of psychopathological distress. The Spanish version of the SCL-90-R

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has shown high internal consistency, ranging from .81 to .90 (González de Rivera et al., 1989).

**Experience of Caregiving Inventory (ECI)** (Szmukler et al., 1996). The ECI assesses the experience of caring for an individual with a severe mental illness. The questionnaire consists of 66 items with a five-point Likert-type scale (ranging from 0 to 4), grouped into eight negative dimensions and two positive ones. Each scale has a satisfactory reliability falling between .74 and .91. The Spanish version obtained satisfactory internal consistency of 0.84 for the Positive dimension and 0.93 for the Negative dimension (Sepúlveda et al., *in press*). Higher scores indicate a greater overall positive or negative appraisal toward caregiving.

**Level of Expressed Emotion Scale (LEE)** (Cole & Kazarian, 1988). The LEE assesses the emotional environment at home as it is perceived by patients and their close relatives. The questionnaire contains 60 true or false items which generate a total EE score ranging from 60 to 120, with higher scores indicating higher levels of EE. The LEE is also comprised of four subscales: 1) intrusiveness, 2) emotional response to the patient's illness, 3) negative attitude toward the patient's illness and 4) low levels of tolerance and high expectations for the patient. The final Spanish version of the LEE scale (LEE-S), which has been used in the present study, was shortened to 45-items and it presented adequate psychometric properties (Sepúlveda et al., 2012).

## **Procedure**

Carers were voluntarily recruited from the above mentioned Eating Disorders Services, from consecutive admissions or hospital outpatient services, over a period of two years (June 2010-2012). The sample was classified by gender, with mothers and fathers as independent informants of the emotional environment at home. The research was reviewed and approved by an institutional review board and ethical approval was granted (R-009/10).

## **Translation and Cultural Validation**

The following translation procedures were followed for the FQ, in accordance with the guidelines for instrument translation across countries proposed by Muñiz, Elosua, & Hambleton (2013): (a) two independent translations of the original 20-item version were carried out from English into Spanish by two expert translators with knowledge of psychology and psychopathology; (b) translation back into English was carried out by

another expert translator; (c) re-translated material was found to be accurate after a comparison of the direct and re-translated versions offered by the translator and the researchers; and (d) the definitive version is presented in this paper.

### Data Analysis

Data from the same family have been analyzed separately by classifying subjects by gender as if they were independent samples rather than correlated ones. Exclusion criteria were set at three missing responses in each questionnaire. When a maximum of three items were incomplete, individual missing values were replaced with the item mean score, separately for each gender. A series of analyses were conducted to test the psychometric properties of the FQ scale:

**Confirmatory Factor Analysis (CFA).** In order to examine the dimensionality of the FQ, we estimated a CFA model following recommendations for providing validity evidence based on internal structure, described by Rios and Wells (2014). LISREL 8.8 was used for mothers and fathers separately (Jöreskog & Sörbom, 2001). This model replicated the original structure proposed by the FQ. The FQ items were treated as categorical because of their limited four-point response scale. In terms of univariate normality tests, several items in both groups revealed significant skewness and kurtosis p-values, and multivariate normality tests were also significant for both groups, suggesting departure from normality. However, the measures of relative multivariate kurtosis for the present samples were 1.129 for mothers and 1.097 for fathers, values considered relatively small, suggesting that collectively the multivariate distributions are reasonably normal (Mardia, 1970; Vieira, 2011). The Robust Diagonally Weighted Least Squares (DWLS) estimation method was used, which adjusts the model to a matrix of polychoric correlations and requires a calculation of the asymptotic covariance matrix. Satorra-Bentler chi-square (Satorra & Bentler, 1994) was also used to correct for the effects of a possible violation of the normality assumption. Following several authors' recommendations (Hu & Bentler, 1999), the fit of the model was determined by a combination of *Satorra-Bentler Scaled Chi-Square* ( $\chi^2, p > .05$ ), *Root Mean Square Error of Approximation* (RMSEA < .08) with its Confidence Interval, *Comparative Fit Index* (CFI > .95), and *Non-Normed Fit Index* (NNFI > .90) fit indices. The CFA model considered a bifactor structure where each FQ item was allowed to load onto one of two correlated factors. This model was identified by fixing the variance of the latent variables to 1.0.



**Descriptive Data.** Descriptive statistics were calculated and gender differences in the validated Family Questionnaire-Spanish version (FQ-S) were explored using the Mann-Whitney U Test.

**Reliability.** Scale reliability was assessed by calculating Cronbach's alpha for the two samples separately (mothers and fathers). Corrected item-scale Pearson correlations were also calculated.

**Other Evidence Indicating Validity.** Convergent validity was examined differentiating by gender. The strength of the association between subscale scores of the FQ-S, the negative dimension of the ECI, and the levels of psychopathology (GSI index) in carers was examined using Spearman correlations. The concurrent validity was also explored by examining the association between the FQ-S and the LEE-S.

## Results

Before carrying out a Confirmatory Factor Analysis, data were submitted to EFA using PCA and varimax rotation with Kaiser normalization, in order to replicate the results of the original version of the scale. Two factors had eigenvalues greater than 1 and a visual inspection of the scree plot indicated that a two-factor structure was appropriate, explaining 37.1% of the total variance for the sample of mothers and 32.7% for the sample of fathers.

### Confirmatory Factor Analysis

To examine whether the Spanish version of the FQ contained the reported underlying bifactor structure, we conducted a CFA for each sample, specifying a model with two latent variables that represented each of the subscales, which predicted each of the items on their respective subscales.

Table 1 displays the CFA factor loadings for mothers and fathers respectively. In either solution, factor loadings were generally appropriate ( $\geq .30$ ) except for item 17, which presented small values. The fit for the bifactor CFA model was: SB  $\chi^2 = 323.432$  ( $df = 169$ ,  $p < .01$ ), RMSEA = .067 (.056 - .078), CFI = .95, and NNFI = .95 for mothers; SB  $\chi^2 = 273.034$  ( $df = 169$ ,  $p < .01$ ), RMSEA = .058 (.046 - .071), CFI = .95, and NNFI = .94 for fathers. Fit indices are consistent with an appropriate overall model fit. All parameters were statistically significant. Correlations between EOI and CC were .43 for mothers and .44 for fathers.

**Gender Differences in FQ-S Scoring**

Gender differences in the FQ-S scores using the Mann-Whitney test yielded a mean of 21.10 ( $SD = 5.45$ ) for mothers and 20.54 ( $SD = 4.49$ ) for fathers in the CC subscale: these differences were not statistically significant ( $z = -0.68$ ;  $p = .49$ ). Regarding the EOI subscale, a mean of 27.20 ( $SD = 4.4$ ) for mothers and 25.95 ( $SD = 4.0$ ) for fathers were found; these differences were statistically significant ( $z = -2.71$ ;  $p = .01$ ). From the sample, 37.4% of the mothers showed high CC compared with 33% of the fathers, while 55.2% of the mothers yielded high EOI compared with 42.5% of fathers, following the cut-off points proposed for each subscale. These differences were statistically significant only for the EOI subscale ( $\chi^2 = 6,152$ ,  $df = 1$ ,  $n = 382$ ,  $p = .01$ ).

**Reliability and Item-scale Correlations**

Internal consistency was estimated by Cronbach's  $\alpha$  coefficient demonstrating acceptable reliability for both samples. For mothers, the Cronbach's alpha for the CC subscale was .83 and for the EOI subscale it was .72. For fathers, however, the values were slightly lower: the Cronbach's alpha for the CC subscale was .78 and for the EOI subscale it was .69.

As shown in the Table 1, the 10 items of the CC scale inter-correlated between .11 and .63 for mothers and between .22 and .62 for fathers. Corrected item-scale correlations for the EOI scale ranged from .11 to .55 for mothers and from .16 to .51 for fathers. The item-scale correlation of Item 17 was low, suggesting that it is not as closely associated with the rest of the scale as the other items are.

**Convergent and concurrent validity**

Regarding the convergent and concurrent validity of the FQ-S scale by gender (see Table 2), significant correlations of moderate to high strength were found between the CC subscale and the LEE-S total scale and its subscales among the sample of mothers. Moreover, the EOI subscale showed small, but significant correlations with 'Hostility', 'Lack of Tolerance', and the LEE-S total score. Regarding the sample of fathers, significant correlations of a moderate to strong relationship were found between the CC subscale and the LEE-S total scale and its subscales, except for the 'Intrusiveness' subscale in which the association was not significant. Finally, significant associations of moderate strength were found between the EOI subscale, the LEE-S total, and 'Lack of

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Tolerance'. Regarding the convergent validity of the scale, significant associations of moderate strength were found between the ECI negative dimension and the GSI index and the CC and the EOI subscales, for both the mothers and fathers; however, the significant correlations between the EOI subscale and the GSI index were lower for both samples ( $\rho = .24, p < .01$ ).

### **Discussion and conclusions**

The primary aim of this study was to adapt and validate the FQ for use with Spanish families of patients with an ED by using CFA. One innovative aspect of the study was that it separated informants within the families, thereby allowing for an examination of differences in EE between mothers and fathers. The sample of 203 mothers and 179 fathers is a large and representative one, ideal for the adaptation of an EE instrument. Our findings are in accordance with the EFA of Wiedemann et al. (2002) which endorsed the use of critical comments and emotional overinvolvement as factors in the original scale. However, the two factors together accounted for 48.7% of the variance in the original scale, whereas in our samples they are slightly lower: 37.1% for mothers and 32.7% for fathers. The CFA has confirmed the validity of the two-factor solution that these authors had proposed by demonstrating an acceptable fit, with better results among mothers as compared to fathers. To date, there have not been any other published studies that provide support for using this factor structure in the analysis of clinical samples.

A content examination of the items with the lowest factor loadings and of the intercorrelations between them may be instructive. For example, item 17 was the item with the lowest factor loading in both versions of the FQ, in the original English and in the Spanish translation. Most of the carers scored high on this item since 'the feeling that sons/daughters are an important part of any father's or mother's life' is an expected condition among them that does not discriminate between healthy family relationships and pathological ones. An amendment of the item may be suggested so that it can be better adapted to the reality of a parent living with a family member with an illness. For example, item 17 could be modified as follows: 'He/she is the most important part of my life'.

The reliability of the CC and EOI subscales was acceptable for mothers, and slightly lower for fathers, although the original subscales yielded better coefficients.

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Intercorrelations between subscales followed expected patterns: the EOI scale appeared to be more heterogeneous than the CC scale. In line with Wiedemann et al. (2002), we also believe that EOI is a complex construct which is difficult to define. For example, item 1 for mothers may express a critical response to the illness but at the same time reveals their overprotectiveness and overconcern regarding their children; something that does not occur among fathers. Additionally, item 9 presents a low correlation with the total EOI scale for both mothers and fathers. This item may need further clarification, as it expresses an ambiguous coping response to the illness, suggesting both overconcern about the illness, through avoidance, as well as possible criticism, if the family member responding to the questions places more emphasis on the conditional statement 'if something bothers me'.

We also examined the concurrent validity of the scale. For mothers, the CC subscale was found to have significant and high correlations with the Level of Expressed Emotion (LEE-S) total score and its subscales (close to .50), while the EOI subscale presented lower correlations with the LEE-S scale and not all of these were significant. For fathers, it is worth highlighting that the CC subscale correlated significantly with the LEE-S total scale and almost all the subscales, while the EOI correlated significantly with the LEE-S total scale and only one of the subscales. One possible explanation could be that the LEE-S and the FQ-S examine the EE construct in two different ways. The LEE-S is organized into four subscales that are difficult to define, although they mainly reflect the critical comments component of EE, with low, and in some cases non-significant, correlations among them (Sepúlveda et al., 2012). The second instrument is organized into two scales which are clearly defined and have been widely used in clinical settings. Convergent validity was established with moderate to high correlations with other reliable instruments developed to assess caregiving experience, supporting the association between EE and psychological family variables, as well as the prognostic significance of EE in carers' well-being, both among ED samples (Kyriacou et al., 2008; Sepúlveda et al., 2012) and other clinical samples (Möller-Leimköhler, 2005).

As expected, mothers showed higher EOI compared to fathers, a difference also observed in the study by Wiedemann et al. (2002), and in other studies with ED samples (Kyriacou et al., 2008; Szmukler et al., 1996). Our results also support evidence suggesting that women tend to become more emotionally overinvolved in their family relationships. A possible explanation of these differences is that mothers are usually the

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ones primarily responsible for providing formal or informal care for their children. Consequently, mothers are a more representative sample than fathers to assess EE, and to whom the maintenance model in EDs can offer a better fit and understanding of the family strain process in EDs. Another potential explanation for the lower EE among fathers could be related to their better adaptive response to the illness and could suggest their use of effective coping strategies. Regardless, fathers may need to be actively encouraged to be more involved in research and clinical contexts so as to fully assess their role in the family context.

Overall, the Spanish version of the FQ presents good reliability, satisfactory convergent validity and acceptable concurrent validity, which allow for the use of the instrument in Spanish families of patients with an ED, although some changes may be necessary to achieve a better fit of the two-factor model (i.e. the proposed modification of the item 17). The instrument obtained better psychometric properties when it was used by mothers than fathers; therefore we encourage the use of independent standards for both genders when developing gender-sensitive instruments. Differences between mothers and fathers in their emotional response to the illness also appear to support the importance of considering a gender-specific approach when carrying out interventions that aim to reduce EE in carers. More specifically, the observed gender differences in EE highlight the importance of improving the tendency of over-involvement in mothers and withdrawal and criticism in fathers. However, fathers' tendency to be emotionally overinvolved in the course of the illness should be viewed as just as important an issue as their level of criticism when working with them in family therapy.

There are several limitations that should be noted. First, the measure's sensitivity to change before and after family intervention has been explored in previous studies (Pepin & King, 2013). Here, however, we suggest that additional attention should be given to assessing test-retest reliability. Further evidence of the predictive validity of the instrument in assessing efficacy of treatment and relapse rate through cross-sectional models and longitudinal prediction studies is also recommended. A recent study that used the FQ to measure the instrument's sensitivity to change after intervention, showed a significant reduction in EE over time among Spanish families (Gutiérrez, Sepúlveda, Anastasiadou, & Medina-Pradas, 2014). It would be also advisable to use both objective and subjective measures of EE from both points of view (the child's and the carers') (Duclos et al., 2012) as parents may attempt to conceal their criticism or concern in a face-to-face

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interview context. In this context, the use of self-report measures may be more advantageous. Finally, an important aim of future research would be the examination of the FQ's psychometric properties in other clinical samples in order to examine its generalizability.

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**Table 1.** CFA factor loadings and corrected item-total correlations of the FQ for mothers and fathers.

	CFA bifactor for mothers	CFA bifactor for fathers	Corrected item-scale correlation for mothers	Corrected item-scale correlation for fathers
<i>Factor 1: Criticism (CC)</i>				
<i>(10 ítems, Alpha de Cronbach .83)</i>				
FQ-2. Tengo que pedir continuamente que haga las cosas [I have to keep asking him/her to do things].	.48	.54	.40	.44
FQ-4. Él/ella me molesta [He/she irritates me].	.60	.30	.48	.22
FQ-6. Tengo que intentar no criticarle/la [I have to try not to criticize him/her].	.59	.58	.47	.43
FQ-8. Es difícil para nosotros estar de acuerdo en cosas [It's hard for us to agree on things].	.74	.64	.59	.49
FQ-10. No aprecia lo que hago por él/ella [He/she does not appreciate what I do for him/her].	.45	.39	.40	.32
FQ-12. En ocasiones, él/ella me pone de los nervios [He/she sometimes gets on my nerves].	.80	.82	.63	.62
FQ-14. Él/ella hace algunas cosas por rencor [He/she does some things out of spite].	.72	.55	.57	.46
FQ-16. Cuando él/ella quiere constantemente algo de mí, me molesta [When he/she constantly wants something from me, it annoys me].	.71	.49	.58	.41
FQ-18. Tengo que insistir que él/ella se comporte de forma diferente [I have to insist that he/she behave differently].	.64	.68	.48	.54
FQ-20. Estoy a menudo enfadado con él/ella [I'm often angry with him/her].	.73	.76	.62	.61

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<i>Factor 2: Emotional Overinvolvement (EOI)</i>				
<i>(10 ítems, Alpha de Cronbach .72)</i>				
FQ-1. Tiendo a descuidarme a mi mismo/a por él/ella [I tend to neglect myself because of him/her].	.41	.50	.29	.40
FQ-3. Pienso a menudo qué va a ser de él/ella [I often think about what is to become of him/her].	.68	.57	.53	.34
FQ-5. Sigo pensando en las razones por las que enfermó [I keep thinking about the reasons for his/her illness].	.43	.54	.37	.40
FQ-7. No puedo dormir a causa de él/ella [I can't sleep because of him/her].	.71	.67	.51	.51
FQ-9. Cuando algo me molesta de él/ella, yo me lo guardo para mí mismo/a [When something about him/her bothers me, I keep it to myself].	.52	.35	.31	.20
FQ-11. Percibo mis propias necesidades como menos importantes [I regard of my own needs as less important].	.52	.45	.46	.39
FQ-13. Estoy muy preocupado por él/ella [I'm very worried about him/her].	.72	.71	.55	.48
FQ-15. Pensé que yo podría llegar a enfermar [I thought I would become ill myself].	.54	.39	.37	.27
FQ-17 <sup>a</sup> . Es una parte importante de mi vida [He/she is an important part of my life].	.14	.22	.11	.16
FQ-19. He renunciado a cosas importantes con la finalidad de poder ayudarle/la [I have given up important things in order to be able to help him/her].	.47	.43	.34	.33

**Note.** All item-scale correlations at  $p < .01$ .

<sup>a</sup>Proposed modification of item 17: Es la parte más importante de mi vida

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**Table 2.** Correlations between the two subscales scores of the FQ-S and, the four subscales scores and total score of LEE scale ( $N = 45$ ), the GSI index and the ECI negative dimension for mothers and fathers (mothers  $N = 203$  and fathers  $N = 179$ ).

	FQ EOI	FQ CC	LEE-S Intrus.	LEE-S Hostility	LEE-S Negative Attitude	LEE-S Lack Tolerance	LEE-S Total	GSI	ECI negative
<i>MOTHERS</i>									
<i>FQ Criticism</i>	.43**	--	.43*	.50**	.45**	.59***	.64***	.36***	.50***
<i>FQ Overinvolvement</i>	--	.43**	.27	.33*	.24	.32*	.39**	.24**	.53***
<i>FATHERS</i>									
<i>FQ Criticism</i>	.44**	--	.11	.59***	.49**	.44**	.57***	.32**	.41***
<i>FQ Overinvolvement</i>	--	.44**	.27	.23	.13	.39**	.37*	.24**	.53***

**Note.** \* Correlation is significant at the .05 level (2-tailed)  
 \*\* Correlation is significant at the .01 level (2-tailed)  
 \*\*\* Correlation is significant at the .001 level (2-tailed)

**STUDY 3**

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**IMPACT OF CAREGIVING EXPERIENCE ON  
MENTAL HEALTH AMONG CAREGIVERS:  
A COMPARISON OF EATING DISORDER  
PATIENTS WITH PURGING AND NON-PURGING  
BEHAVIORS**

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*Sepulveda, A. R., Anastasiadou, D., Pellegrin, P., Andrés, P.,  
Graell, M., Carrobes, J. A., & Morandé, G.  
Eating and Weight Disorders, 19(1), 31-39.*

**Abstract<sup>3</sup>**

**Purpose.** Differences in mental health among primary caregivers of eating disorder (ED) patients with purging and non-purging behaviors were explored and predictors of psychopathological distress among caregivers were also determined. **Method.** 177 caregivers, ranging from 29 to 75 years of age, of adults and adolescents with an ED participated in the study. The caregivers completed self-report assessments related to psychopathological distress (GSI), specific experience of caregiving (EDSIS) and expressed emotion (LEE). **Results.** A statistically significant difference in psychopathological distress was presented by caregivers of patients with purging behaviors (38.9%) compared with non-purging ones (25%), using a GSI cut-off point. In patients who purged, caregiver's intrusiveness and difficulties related to eating behavior accounted for 25% of the variance and in those who did not purge, difficulties related to eating behavior, guilt, social isolation, hostility and negative attitude toward illness accounted for 44% of variance. **Conclusions.** The differences observed indicate the importance of identifying purging as a significant clinical marker of increased risk of psychopathological distress in caregivers.

**Keywords.** Purging Behaviors; Caregivers; Eating Disorders; Psychopathological Distress; Associated Factors

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<sup>3</sup>The following article was adapted to follow the *Eating and Weight Disorders* guidelines

## **Introduction**

Purging behaviours are presented in all subtypes of eating disorders (ED) (1-6). There is strong scientific research to support the fact that patients with purging behaviors experience more intense psychopathological distress when compared to their non-purging counterparts (7-10).

### **The burden of caregiving for an individual with an ED**

Clinical evidence based mostly on quantitative research shows that families who care for a relative with an ED suffer significant levels of distress, burden, maladaptive coping and expressed emotion (EE). These caregivers also report physical and mental health deterioration (11-12).

Several models have been developed to better explain a caregiving experience and understand how to intervene on the dysfunctional patterns of caregiving in order to improve illness outcomes and reduce caregivers' levels of distress. Therefore, by changing caregivers' negative illness perceptions (13), by reducing feelings of dependency and stigma (14), family conflict and lack of social support (15), their caregiving experience may be improved. Furthermore, higher weekly contact hours with their relatives and high EE levels were associated with a negative caregiving experience, which in turn was associated with the caregivers' mental health status (14). Recently, Padierna et al. (2012) (16) added variables associated with caregivers' demographic characteristics (i.e. being divorced, having a low education level, among others) to predict the burden of caregiving.

The caregiving experience can also carry a devastating effect on the interpersonal relationship between parents and their son or daughter with an ED (17). Dysfunctional interpersonal patterns, such as high levels of EE, may serve as maintaining factors of the illness (18) which can be improved through family-based treatment interventions (19-21).

The above-mentioned studies include several limitations which highlight the importance of examining specific facets of the caregiving experience in more detail (16) and the impact of different diagnostic types (binge/purge versus restrictive) or different types of disorders (AN versus BN) on caregiver outcomes (14,22). Studies aimed at examining these same facets outside of the psychiatric hospitalization setting, such as outpatients settings where the illness condition is less severe, are also called for (13,15).



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Finally, it has been pointed out that the use of heterogeneous samples, as opposed to those consisting of only adolescents with short illness duration, is necessary, as well as the use of samples of older patients (14). In the present study, some of these limitations may be addressed.

#### **The harmful burden of purging behaviors among caregivers**

There has been little scientific research on the impact of specific ED behavioral disturbances on caregivers' wellbeing. In a study by Viesselman & Roig (1985) (23), which compared three groups of patients (binge-eating vs. binge-eating and purging behaviors vs. food restriction), the authors found more depressive symptoms in the mothers of the group with binge-eating and purging behaviors. More recently, in a study by Sepúlveda et al. (2008) (24), caregivers of patients with BN endorsed twice as much dysregulated behaviour and general caregiving difficulties comparing with caregivers of patients with AN. The impact of purging behavior on families' mental and physical health was first mentioned in a study by Martin et al. (2011) (25), in which the presence of purging behaviors was shown to be the second most important predictor of low health-related quality of life among caregivers of patients with an ED, after the importance of the caregiver-patient relationship.

Thus, the objective of this study is to explore the differences in mental health among primary caregivers of ED patients with purging and non-purging behaviors and to determine predictors of psychopathological distress among carers.

Following a dimensional perspective on eating disorders, according to which special emphasis is placed on changing ED disturbed behaviors and other clinical symptoms (26), our hypothesis was: primary caregivers of a patient with purging behaviors would report a more negative caregiving experience in terms of EE, health status and ED specific impact, compared to caregivers of a patient with non-purging behaviors. Moreover, in each group of caregivers, different psychological factors associated with their health status are expected to be identified.

## **Method**

### **Participants**

The study group consisted of 177 caregivers of patients diagnosed with an ED. Although a maximum of two caregivers from each family were invited to participate,

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data were analyzed from only the primary caregiver (the caregiver with the most contact with the patient) to avoid problems with lack of independence.

### **Design and Procedure**

A cross-sectional and descriptive study based on self-reported questionnaires was conducted among primary caregivers of patients with an ED. The majority of the caregivers were voluntarily recruited from several Spanish Eating Disorders Services: from consecutive admissions or outpatient services at two public hospitals, the Eating Disorders Service at the Marques of Valdecilla Hospital (16.9% of caregivers) and the Child and Adolescent Psychiatric Section at the Niño Jesus University Hospital (49.7% of caregivers), and from the Spanish Eating Disorders Caregivers Association (ADANER-Madrid) (33.3%). Information about the patients' ED diagnoses was provided by mental health professionals at the respective hospitals following DSM-IV-TR diagnostic criteria (American Psychiatric Association, 2002). In the case of ADANER, the ED diagnosis was not confirmed by a medical practitioner but was reported by caregivers of patients and members of the association who had received (or were receiving) treatment for their relative's ED through the Spanish mental health system. Data collection was conducted over a period of two years (January 2007-09). Ethics committee approvals at the hospitals were granted for this study (R-009/10).

Caregivers were divided into two groups, a purging and a non-purging group, on the basis of self-reported purging behaviors of their relatives over the 4 weeks prior to assessment. Caregivers whose relatives with an ED had vomited, used laxatives and/or diuretics were classified as caregivers of patients who purge. Caregivers of patients with other behavioral disturbances that did not include purging behaviors or included other methods of controlling weight gain, such as food restriction or exercise, were classified as caregivers of patients who do not purge.

### **Assessment Instruments**

Caregivers completed a demographic questionnaire that included details about themselves (age, sex, marital status, employment status, education level). The patient's clinical variables included information about the patient, such as gender, age, age of diagnosis, onset of the illness, current status of treatment (i.e. inpatient, day hospital outpatient, without treatment) and the presence of disordered eating behaviors. The

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illness duration was calculated by subtracting the age of illness onset from the current age.

**The Eating Disorders Symptom Impact Scale (EDSIS)** (24) was used to assess caregivers' negative appraisals of specific aspects of caregiving in EDs. The instrument has 24 items based on Likert-type scale questions (0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4 = nearly always) and four subscales (Nutrition, Guilt, Dysregulated Behavior and Social Isolation). Higher scores indicate a worse specific caregiving experience related to the ED. Cronbach's alpha for the total instrument is excellent ( $\alpha = 0.91$ ) in an English population (24). The Spanish validation of the instrument (27) showed good internal consistency of the total scale ( $\alpha = 0.88$ ). Cronbach's alpha for the current study was  $\alpha = 0.89$ .

**The Level of Expressed Emotion-Spanish Version (LEE-S)** (28) was developed to measure the perceived emotional climate at home. This relative version of the LEE-S requires the close relative to evaluate his or her relationship with the patient. The 60-item scale is based on the EE construct, which is rated in a true-false format. The scale generates an overall score for the level of EE as well as a score for each of the four response patterns: Intrusiveness, Emotional response, Attitude toward illness, and Tolerance and Expectations. Following an Exploratory Factor Analysis, a 45-item Spanish version of the LEE scale was derived from the original version of the LEE scale for relatives, which consisted of four subscales: Negative Attitude toward Illness, Intrusiveness, Hostility toward Patient and Tolerance/Coping with Illness, whose internal consistency ranged from 0.73 to 0.86 (29). Cronbach's alpha for the current study was  $\alpha = 0.84$ .

**The General Symptom Index (GSI)** is one of the most widely used indexes of psychopathological distress, derived from the Symptom Check List (SCL-90) (30). The SCL-90 is comprised of 90 items organized within 9 symptom dimensions and scales using Likert scoring (1 to 4). The GSI is the sum of 90 item scores divided by 90. The Spanish version of the SCL-90-R (31) showed high internal reliability ranging from 0.81 to 0.90. Direct scores of  $\geq .80$  in men and of  $\geq 1.12$  in women suggest the presence of a psychiatric disorder, which has been reported previously by González de Rivera et al. (2002) (30). Cronbach's alpha for the current study was  $\alpha = 0.98$ .

### **Statistical analyses**

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Data were analyzed using the statistical software package SPSS 15.0 for Windows (32). Sociodemographic variables were examined with *t*-tests and chi-squared tests were used for each categorical variable. A non-parametric Kolmogorov-Smirnov test was used as independent variables were not normally distributed in the sample. A non-parametric Mann-Whitney U test with Bonferroni correction for multiple comparisons was used for the eleven continuous variables. Statistics were computed with a threshold for statistical significance set at  $p = .004$ . Spearman correlations ( $\rho$ ) were used to examine the strength of associations between total GSI scores and the other measures. The first linear regression analysis (successive stepwise model), with the GSI score as the dependent variable and purging/non-purging behavior condition and psychological factors (four subscales of the EDSIS and four subscales of the LEE-S) as the independent variables, was conducted to predict psychopathological distress in the total sample of primary caregivers.

The sociodemographic variables were also entered after dichotomizing the data. Data for purging behavior (the only dichotomized variable that was finally included in the model) were categorized as low (0) for non-purging behavior, whereas data were categorized as high (1) for purging behavior. The variable “treatment received” was categorized as presenting “Severe ED psychopathology” (1) all patients who received “Hospitalization” or “Day Hospital” treatment and as “Non severe ED psychopathology” (0), patients who received “Ambulatory care” or “Without treatment”. Another two multiple regression analyses were conducted using the same variables (except for the presence of purging behaviors) by separating caregivers whose relatives were presenting purging behaviors and those whose sons/daughters were not. A partitioning of explained variance ( $r^2$ ) was then conducted to ascertain the unique variance that could be attributed to each of the variables. All  $p$  values were two-tailed and statistical significance was set at  $p < .05$ .

## **Results**

### **Demographic data and clinical features of caregivers and patients**

The sample consisted of 162 women and 15 men, ranging in age from 29 to 75 years ( $M = 48.8$ ;  $SD = 7.4$ ). 84% of caregivers were married or living with their partner and 52.9% of them had a full or part time job versus 47.1% who were unemployed or retired. No significant differences were found between caregivers of patients with

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purging behaviors and non-purging ones, in terms of education level, marital status and employment status. Table 1 summarizes patients' demographic data and clinical features. The patient's ages ranged from 13 to 34 years ( $M = 19.37$ ,  $SD = 5.58$ ). There were significant differences in the age, the age of the illness onset and in the age of the diagnosis between the two groups, in which the patients with purging behaviours had higher scores in these variables. The difference for the illness duration was also nearly significant ( $z = -1.85$ ,  $p < 0.06$ ).

As shown in Table 1, 17.1% of the purging group and 32.0% of the non-purging group were hospitalised. After dichotomizing the data, 30% of the purging group of patients and 70% of non-purging group showed severe ED psychopathology, in which 52% were caregivers of patients with AN-R.

#### **Differences in psychological variables between purging and non-purging groups**

A statistically significant difference in psychopathological distress (GSI) was presented among caregivers of patients with purging behaviors (38.9%) compared with non-purging ones (25%), using a GSI cut-off point ( $\chi^2 = 3.79$ ,  $df = 1$ ,  $p = .05$ ). Table 2 summarizes the mean scores of psychological variables and differences between caregivers, using Mann-Whitney test for multiple comparisons. When a Bonferroni adjustment to the alpha level was applied, the number of significantly different comparisons between purging and non-purging groups dropped from 4 to 2 ( $p < .004$ ). In this manner, caregivers of patients who purge scored higher on EDSIS Dysfunctional Behaviors ( $z = -3.73$ ;  $p = .001$ ) and Social Isolation scales ( $z = -3.06$ ;  $p = .002$ ).

#### **Association between psychopathological distress and other psychological variables**

Spearman correlations between GSI and LEE-S and EDSIS subscale scores yielded significant and positive correlations for all primary caregivers (Spearman's  $\rho = .24$  to  $.60$ ,  $p < .01$ ). After separating caregivers into purging and non-purging groups, correlations between GSI and EDSIS subscale scores were significant and positive for both groups of caregivers (purging group, Spearman's  $\rho = .31$  to  $.48$ ,  $p < .01$  and non-purging group, Spearman's  $\rho = .44$  to  $.67$ ,  $p < .01$ ). However, for caregivers of patients who purge, significant and positive associations between GSI and LEE-S subscale scores were only found between GSI and the LEE total score (Spearman's  $\rho = .25$ ,  $p = .035$ ). Regarding the group of caregivers of patients who do not purge, significant and positive

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associations were found between all GSI and LEE subscales with correlations ranging from .26 to .45 ( $p < .05$ ).

#### **Predictive psychological distress models for purging and non-purging group**

We adjusted three predictive multiple regression models (successive stepwise models) of psychological distress (GSI scores), firstly, for the whole sample of caregivers and secondly, by separating each group of caregivers (caregivers of patients who purge and do not purge). The subscales of each one of the other two dimensions explored have been separately included in the model. Thus, whether the same dimensions related to EE and specific aspects of caregiving were present in the equations for the purging and non-purging groups could be observed. The final models are summarized in Table 3.

The explanatory capacity ( $R^2$ ) for the whole sample as well as for the two groups of caregivers explained a proportion of variance between 25% and 44%. Regarding the whole sample of caregivers and similarly to the findings for the two groups of caregivers, the highest loading factor was found in the Impact of Nutrition ( $\beta = .42$ ,  $p = .001$ ), followed by Guilt ( $\beta = .23$ ,  $p = .001$ ), the presence of purging behaviors ( $\beta = .14$ ,  $p = .016$ ), Intrusiveness ( $\beta = .14$ ,  $p = .021$ ) and Negative Attitude toward the Illness ( $\beta = .14$ ,  $p = .024$ ). The whole model accounted for 39% of variance in GSI scores ( $F(6,168) = 19.52$ ,  $p = .001$ ). After controlling for patient's age and age of the illness onset, the model accounted for 38.6% of the variance in the caregivers' level of distress with the same variables contributing to the model. If controlling for illness duration, the model accounted for 37.6% of the variance and the Attitude toward the Illness did not contributed to the model.

For the purging group, the model accounted for 25% of the variance in GSI total scores ( $F(3,70) = 8.99$ ,  $p = .001$ ). As shown by the beta weights, first, GSI scores was significantly associated with higher Nutrition Impact ( $\beta = .44$ ,  $p = .001$ ) and higher Intrusiveness ( $\beta = .24$ ,  $p = .023$ ). For non-purging group, the model accounted for 44% of the variance in GSI total scores ( $F(4,94) = 19.92$ ,  $p = .001$ ), it was significantly associated with higher Nutrition Impact ( $\beta = .47$ ,  $p = .001$ ), higher levels of Guilt ( $\beta = .28$ ,  $p = .002$ ), and Negative Attitude toward Illness ( $\beta = .18$ ,  $p = .035$ ). After controlling for patients' age and age of the illness onset, the model for the purging group accounted for 21% and for the non-purging group 44% of the variance in the caregivers' level of distress with

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the same variables contributing to the model. If controlling for illness duration, the model accounted for the same percentage of the variance in both groups (44% vs. 20%).

### **Discussion**

The aim of this study was to determine the factors associated with the psychopathological distress of caregivers of patients with an ED.

There is strong scientific research to support the fact that patients with purging behaviors experience more intense psychopathological distress when compared to their non-purging counterparts (6, 8-10, 23, 28). It seems that high levels of distress can spread to their caregivers as problems related to specific ED symptoms (vomiting, laxative use, among others) and issues related to their role as caregivers may trigger negative caregiving experiences, such as social isolation and conflictive situations at home. This may further increase the level of psychopathological distress they experience. Our findings are also supported by the study by Martin et al. (2011) (25), which showed that purging behaviors of people with an ED, especially vomiting, had a negative impact on the family's wellbeing and quality of life. Thus, it is crucial to identify purging as a significant clinical marker not only of increased risk of psychopathology in patients but also of presenting a greater impact on caregivers' health.

In the present study, a statistically significant difference in psychopathological distress was presented among caregivers of patients with purging behaviors compared to non-purging ones, using a GSI cut-off point. However, the directionality of this relationship is not clear, whether patients had developed purging behaviors as a consequence of familiar problems and distress in their families or whether the caregivers felt more distressed because of the presence of purging behaviors in their sons/daughters when compared to patients with non-purging type of an ED.

One important finding of the present study was that variables associated with caregivers' psychopathological distress were different for caregivers of relatives who purged, except for the Nutrition Impact of the EDSIS scale, which explained most of psychopathological distress for both groups of caregivers. Regarding the whole sample of caregivers, the Nutrition Impact of the EDSIS scale followed by Guilt were the variables with the highest predictive value for caregivers' psychopathological distress. This result is supported by Sepúlveda et al. (2012) (33) and Raenker et al. (2012) (34) in a Spanish and British sample respectively. Moreover, Coomber & King (2012) (35) in an

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Australian sample found a strong positive association between EDSIS Mealtime difficulties, Guilt and GHQ-12 scores. In accordance with our findings, that problems related to the nutritional support of patients with an ED and feelings of guilt were the strongest contributors to GSI among caregivers, we can suggest that caregivers may benefit from using practical strategies such a nutritional support to their sons/daughters and from changing their dysfunctional illness perceptions. These results are also supported by Sepúlveda et al. (2008) (19) following the “Maudsley ED Collaborative Care” intervention.

Examining each group of caregivers separately, it appears that each one of them perceives the illness in a different way; thus, purging behaviors seem to lead the caregivers of individuals who purge to intrude into the patient’s privacy and to experience difficulties in managing his/her eating habits, taking into account that parents are worried about the serious physical risks associated with purging behaviors (37) as well as the high levels of secrecy in their patient’s behavior.

For caregivers of individuals who do not purge the majority of whom had a diagnosis of AN-R (64.0%), feelings of guilt were associated with their psychological distress. Our results are contrary to the ones reported in the study of Sepúlveda et al. (2008) (24) in which the caregivers of patients with AN reported less feelings of guilt compared with the caregivers of patients with BN. Regarding EE, a negative attitude toward the illness (“I don’t help him/her when he or she is upset or feeling unwell”, “I get angry with him/her for no reason”) was associated with GSI for this group of caregivers. Kazarian et al. (1990) (28) found a strong, positive correlation between Negative Attitude toward Illness and Critical Comment subscales of the Camberwell Family Interview (CFI) (29). Hence, it can be deduced that caregivers may be critical and develop negative feelings toward a patient who is passive, powerless or a victim of his/her illness by using restriction as a manifestation of his/her discomfort instead of more apparent clinical signs, such as vomiting. Kyriacou et al. (2008) (11) also found higher levels of criticism in caregivers of patients with AN when compared to healthy controls.

### **Conclusions**

Our results suggest that identifying purging behavior as a clinical marker associated with increased psychological distress in caregivers of individuals with an ED, may play an important role as a predictor of the illness outcome. As Fairburn, Cooper & Shafran



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(2003) (26) proposed, interventions should target significant behaviors and clinical manifestations of the ED disorder rather than diagnostic criteria. Caregivers of both groups appear to experience difficulties in managing their relative's specific eating habits and report that they lack communication skills to manage the patient's ED specific dysregulated behaviors more effectively (13,24). However, as Zabala et al. (2009) (22) emphasized in their systematic review, it is important to specify the impact of the ED in terms of whether it is specifically related to ED specific symptoms and behaviors or to having a relative with a psychiatric illness. In this manner, various researchers (19-21) reported that psychopathological distress and EE of caregivers appeared to be reduced after administering structured family interventions.

### **Limitations**

This study presents several limitations. Firstly, there is the fact that cross-sectional studies cannot determine causal relationships between variables, and limits the clinical utility of the study, because longitudinal studies showed a high cross-over between AN-R, AN-P and BN. Moreover, the type of sample used was heterogeneous: caregivers were enrolled at different stages of treatment and from different hospitals and associations; therefore, there was a wide range of ages of patients and caregivers. Furthermore, the majority of the diagnoses were established by medical reports provided by health professionals at the respective public hospitals. Thus, a potential bias is added concerning the ADANER sample in which the diagnosis for each patient was reported by caregivers. However, it is worth mentioning that caregivers can have important insights regarding symptomatology severity that are not necessarily observed in clinical settings. It is not clear how valid the symptom checklist used is as a method for caregivers to report observed symptoms. Another limitation was the body mass index of the patient, which was not collected in the study, and perhaps this variable could have influenced the caregiver's psychological distress. However, the diagnosis and the current treatment were included in the analyses and it appears that the explanatory capacity for the three models changes only slightly.

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**Table 1.** Sociodemographic and clinical characteristics of patients with purging and non-purging behaviors, reported by their caregivers<sup>4</sup>.

	Total Sample of patients (N = 177)		Patients with Purging Behaviors (N = 76)		Patients with Non- Purging Behaviors (N = 101)		Z; p-value
	M	SD	M	SD	M	SD	
Age (years)	19.37	5.58	20.46	5.06	18.54	5.83	-3.48; <b>p = 0.001</b>
Mean illness duration (years)	3.94	4.38	4.37	4.49	3.63	4.30	-1.84; p = 0.066
Mean age of illness onset (years)	15.16	3.41	15.72	3.08	14.76	3.59	-2.81; <b>p = 0.005</b>
Age of diagnosis	16.45	4.31	16.89	3.76	16.14	4.65	-2.75; <b>p = 0.006</b>
	Total Sample of patients (N = 177)		Patients with Purging Behaviors (N = 76)		Patients with Non- Purging Behaviors (N = 101)		$\chi^2$ p-value
	N	%	N	%	N	%	
Sex							
Man	10	5.7	3	4.0	7	7.0	$\chi^2 = 0.72$ ;
Woman	165	94.3	72	96.0	93	93.0	p = 0.397
Treatment received							
Ambulatory Care	79	44.6	43	56.6	36	36.0	$\chi^2 = 9.79$ ;
Hospitalization	45	25.4	13	17.1	32	32.0	<b>p = 0.020</b>
Day Hospital	34	19.2	11	14.5	23	23.0	
Without treatment	18	10.2	9	11.8	9	9.0	
Diagnosis							
AN-R	64	36.4	0	0	64	64.0	$\chi^2 = 121.94$ ;

<sup>4</sup>Except for the variable "Diagnosis". This variable was reported by health professionals.

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AN-P	28	15.9	28	36.8	0	0	<b>p = 0.001</b>
BN	27	15.3	27	35.5	0	0	
EDNOS	57	32.4	21	27.6	36	36.0	
Purging Behaviors <sup>5</sup>							
Vomiting & use of laxatives/diuretics							
Yes	75	43.1	75	100.0	0	0	$\chi^2 = 174.00$ ;
No	99	56.9	0	0	99	100.0	<b>p = 0.001</b>
Non-Purging Behaviors							
Food Restriction							
Yes	156	89.7	69	93.2	87	87.0	$\chi^2 = 1.79$ ;
No	18	10.3	5	6.8	13	13.0	p = 0.181
Exercising							
Yes	48	27.6	20	27.0	28	28.0	$\chi^2 = 0.02$ ;
No	126	72.4	54	73.0	72	72.0	p = 0.887

**Note: M, mean score; SD, standard deviation; AN-R, Anorexia Nervosa restrictive type; AN-P, Anorexia Nervosa purging type; BN, Bulimia Nervosa; EDNOS, Eating Disorder Not Otherwise Specified**  
**Bold numbers indicate statistically significant differences between patients with purging behaviors and patients with non-purging behaviors**

<sup>5</sup> As only four patients reported using laxatives or diuretics, all three types of purging behaviors were grouped together.

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**Table 2.** Mean scores of psychological variables and differences between the total sample of caregivers, caregivers of patients who purge and caregivers of patients who do not purge.

	Total sample of caregivers (N = 177)	Caregivers of patients who purge (N = 76)	Caregivers of patients who do not purge (N = 101)	
	M (SD)	M (SD)	M (SD)	Z; p-value
<b>EDSIS Total</b>	35.06 (16.23)	38.46 (15.87)	32.50 (16.11)	<b>z = -2.45; p = 0.014</b>
Nutrition Impact	13.67 (6.00)	13.84 (5.49)	13.53 (6.37)	z = -0.32; p = 0.748
Dysfunctional Behaviors	7.93 (5.88)	9.87 (6.23)	6.48 (5.17)	<b>z = -3.73; p = 0.001</b>
Guilt	9.22 (5.63)	9.62 (5.60)	8.92 (5.66)	z = -0.77; p = 0.440
Social Isolation	4.24 (3.45)	5.13 (3.41)	3.56 (3.34)	<b>z = -3.06; p = 0.002</b>
<b>LEE-S</b>	10.95 (6.03)	11.45 (6.41)	10.58 (5.73)	z = -0.60; p = 0.551
Attitude Toward Illness	1.05 (1.57)	1.15 (1.61)	0.98 (1.54)	z = -0.62; p = 0.538
Intrusiveness	3.22 (2.28)	3.24 (2.35)	3.21 (2.23)	z = -0.05; p = 0.963
Hostility Toward Patient	3.15 (2.74)	3.21 (2.87)	3.11 (2.65)	z = -0.01; p = 0.993
Tolerance or Coping with Illness	3.53 (2.26)	3.86 (2.25)	3.29 (2.26)	z = -1.51; p = 0.131
<b>GSI total</b>	0.89 (0.57)	1.00 (0.57)	0.80 (0.56)	<b>z = -2.55; p = 0.011</b>

**Note:** M, mean score; SD, standard deviation; EDSIS, Eating Disorders Symptoms Impact Scale; LEE-S, Level of Expressed Emotion scale-Spanish version; GSI, General Symptom Index

**Bold numbers indicate statistically significant differences between caregivers of patients who purge and caregivers of patients who do not purge**



### Study 3

**Table 3.** Stepwise multiple regression analysis: Caregiving experience predictors of GSI scores.

Independent Variables	GSI scores		
	Total Sample of	Caregivers of patients	Caregivers of patients who
	caregivers	who purge	do not purge
	$\beta$	$\beta$	$\beta$
<b>(Constant)</b>	-0.10	0.22	-0.05
Purging behavior (yes/no)	0.14*	-	-
Severity ED psychopath.			
<b>EDSIS Scale</b>			
Nutrition Impact	0.44***	0.44***	0.47***
Dysfunctional Behaviors			
Guilt	0.21**		0.28**
Social Isolation			
<b>LEE-S Scale</b>			
Attitude toward illness	0.13*		0.18*
Intrusiveness	0.15*	0.24*	
Hostility Toward Patient			
Tolerance or Coping with			
Illness			
<b>R<sup>2</sup></b>	<b>0.39</b>	<b>0.25</b>	<b>0.44</b>

Note. Beta: standardized coefficient; R<sup>2</sup>: explained variance; \*p < 0.05, \*\*p < 0.01, \*\*\*p < 0.001; EDSIS, Eating Disorders Symptoms Impact Scale; LEE-S, Level of Expressed Emotion scale-Spanish version; GSI, General Symptom Index

Note: Excluded variables for the whole sample: Severity ED psychopathology (p = 0.53), Dysfunctional Behaviors (p = 0.11), Social Isolation (p = 0.07), Hostility Toward Patient (p = 0.43), Tolerance or Coping with Illness (p = 0.98). Excluded variables for purging group: Severity ED psychopathology (p = 0.48), Dysfunctional Behaviors (p = 0.49), Guilt (p = 0.15), Social Isolation (p = 0.31), Negative Attitude Toward Illness (p = 0.47), Hostility Toward Patient (p = 0.35), Tolerance with Illness (p = 0.63). Excluded variables for non-purging group: Severity ED psychopathology (p=0.71), Dysfunctional Behaviors (p = 0.08), Isolation (p = 0.08), Intrusiveness (p = 0.58), Hostility Toward Patient (p=0.07), Tolerance or Coping with Illness (p = 0.77).

## **DISCUSSION**

### **Overall discussion**

Having to live with and care for a loved one suffering from an ED, family members experience a burdensome caregiving experience that includes a large number of hours of daily contact with the patient and adverse consequences, including high emotional arousal and distress (Haigh & Treasure, 2003; Whitney & Eisler, 2005). The families' dysfunctional emotional responses to the ED have been summarized by the concept of EE and have led to research on this topic in EDs. Therefore, EE has proven to be a core factor in the prediction of relapse among ED patients and of better outcomes among carers, when it has been addressed in family-based interventions (Eisler et al., 2000; Goddard et al., 2011).

The present thesis, first, draws upon previous research focused on the emotional experience of caring for a family member with an ED and then carries out validation research in Spain, trying at the same time to fill some gaps in the literature in this field. Some of reasons why the present thesis has been carried out are summarized below:

- First of all, there is a need for reliable and valid assessment of EE among ED carers via self-report instruments instead of interviews. Specifically, in complex clinical settings, self-report instruments can be more advantageous compared with face-to-face interviews given that they are more cost-effective and research-applicable methods of assessing EE, convenient to administer in large clinical samples, with less coding limitations and without additional time required for training interviewers and raters. In addition, the use of self-administered procedures permits a large number of clinicians to utilize these variables to effectively predict relapse across different clinical settings (Kazarian et al., 1990).
- Second, in Spain, there is an absence of valid and reliable self-report instruments that measure relatives' perceptions of EE.
- Third, there is a need to consider a gender-specific approach when examining the caregiving experience and the emotional climate at home. Gender differences in family caregiving have rarely been taken into account, although the few available studies have revealed differences between mothers and fathers in emotional well-being and caregiver experiences (Kyriacou et al., 2008a; Martin et al., 2013; Raenker et al., 2013; Whitney et al., 2005) and even though there is a tendency for emotional

overinvolvement in mothers and criticism in fathers. Further, it is important to note that there is an underrepresentation of fathers in clinical research. Fathers are a “neglected group”, perpetuating the stereotype of overinvolved mother and peripheral father (Cook-Darzens et al., 2005).

- Fourth, there is a need for further examination of the cognitive interpersonal maintenance model in EDs (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). As mentioned before, this model has been developed to better explain the ED caregiving experience and understand how to intervene in the dysfunctional patterns of caregiving in order to improve illness outcomes and reduce caregivers’ levels of distress. However, illness-related symptoms and behaviors (rather than diagnostic categories) and their impact on carers’ emotional reactions to the illness have rarely been taken into account when this model has been used in clinical and research settings.

The principal aim of the present thesis has been to validate two self-report instruments assessing EE among Spanish samples of ED carers and to further explore the interpersonal maintenance model in EDs by considering differentiated illness-related characteristics and gender differences and their impact on family response to the illness. In particular, the specific aims and motives for carrying out each research study are summarized below:

### **Study 1**

The factor structure and the psychometric properties of the Spanish version of the Level of Expressed Emotion scale (LEE; Kazarian et al., 1990) were examined among primary carers of patients with an EE. The starting point of the first study has been the assumption that a family-focused approach in EDs is more reliable than a patient one; for that reason, the relative version of the LEE scale, and not the patient one, was chosen for validation.

The LEE scale was chosen as it was logically constructed from the conceptual framework of EE covering a multidimensional nature of the concept (Vaughn & Leff, 1981). More specifically, Vaughn & Leff (1981) affirmed that in homes with high levels of criticism and emotional overinvolvement, four characteristic attitudes or response styles of relatives are expected: “(1) a high level of Intrusiveness (i.e., making repeated attempts to establish contact or to offer unsolicited help to the patient); (2) a highly Emotional Response to the patient’s illness (i.e., responding with anger or acute

distress); (3) a Negative Attitude toward the patient's illness (i.e., doubting that the patient is genuinely ill; frequently blaming or holding the patient responsible for his or her condition); and (4) low Tolerance and high Expectations of the patient (i.e., because the relatives are not convinced that the patient is genuinely ill, they are generally intolerant of both disturbed behavior and of long-term social impairments)".

### Study 2

The psychometric properties of the Family Questionnaire (FQ; Wiedemann et al., 2002) were examined among another sample of ED carers, with differences between mothers' and fathers' emotional response to the illness considered as well. The instrument was chosen for validation for several reasons: First, it has a clear two factor structure which has been widely used in research studies and also it is briefer and easier to use in clinical settings as compared to the LEE scale. Second, the FQ has been proven to be clearly sensitive to both CC and EOI among carers of patients with EDs (Kyriacou et al., 2008a; Sepúlveda et al., 2009) and effective in family-based interventions aiming to modify unhelpful emotional interaction styles (Goddard et al., 2011; Pépin & King, 2013; Sepúlveda et al., 2010). Finally, the concurrent validity of the previously validated LEE scale may only be assessed through validating another self-report instrument in Spain which measures the same construct.

### Study 3

As mentioned before, food, weight and other illness-related behaviors may take a predominant role within family life and interactions, given that the family becomes reorganized around the eating disorder. The impact of illness-related characteristics on carer outcomes was examined in Study 3. More specifically, the principal aim of Study 3 was to explore if the presence of purging behaviors could affect the power of EE in predicting psychological well-being in carers. In this manner, further evidence could be added to the interpersonal maintenance model in EDs by considering variables that have rarely been taken into account in clinical and research settings before.

Overall, the **key contributions** of the three articles composing the present thesis may be divided in four sections regarding: 1) sample characteristics, 2) instrument validation, 3) gender perspective in emotional response to the illness and 4) further exploration of the interpersonal maintenance model in EDs.

### ***1. Sample characteristics***

In Study 1, a sample of 270 carers of patients with an ED, 186 of whom were primary carers and 84 of whom were secondary, was recruited from the Eating Disorders Service of Hospital of Valdecilla, Santander, Spain, the Child and Adolescent Psychiatric Section of the Niño Jesus University Hospital of Madrid, Spain and the Spanish Eating Disorders Carers Association (ADANER-Madrid), over a period of 2 years (January 2007–2009).

In Study 2, a new and amplified sample of 382 carers of patients with an ED, 203 mothers and 179 fathers, were recruited from the Eating Disorders Service of Hospital of Badajoz, Spain and the Child and Adolescent Psychiatric Section of the Niño Jesus University Hospital of Madrid, Spain, over a period of 2 years (June 2010–2012).

In Study 3, 177 primary carers, the majority being the same primary carers used in Study 1, were recruited from the three Eating Disorders Services mentioned in the Study 1. Primary carers whose sons/daughters had an illness duration of more than 20 years were not included in the sample used for Study 3.

First, it can be assumed that the size of the two samples used for the validation research was adequate, given that both EFA and CFA require a minimum of five subjects per item (Costello & Osborne, 2005). The sample size used for Study 3 was also adequate, respecting the formula given by Tabachnick & Fidell (2001) for calculating the number of predictive variables introduced in multiple regression models ( $N > 50 + 8m$ , where  $m$  = number of independent variables).

Regarding demographic characteristics of the samples, the majority of carers were Spanish, married, with full- or part-time jobs, with medium or high educational levels and they spent more than 21 hours per week in contact with their sons/daughters. There is an apparent homogeneity in our samples which reflects the increased prevalence of EDs among medium-high socioeconomic groups and also the early onset of the illness in adolescence, a period in which most of the carers are primarily responsible for their sons/daughters and spend much of their time in face-to-face contact. Finally, our samples can be considered representative of the target population given that they were recruited from multiple resources: Three public referral hospitals in Spain that attend to a large number of child/adolescent and adult cases of EDs, as well as a Spanish non-profit association for carers which organizes various weekly activities for patients and carers, including self-help interventions.

### ***2. Instrument validation***

Regarding instrument validation, the Spanish versions of the LEE and the FQ have proven to be cost-effective and have shown satisfactory psychometric properties allowing for their use in Spanish families of patients with an ED. The instruments were also well-accepted by families, bearing in mind that families recruited from public hospitals in Spain are often less willing, or even refuse, to participate in research studies considering their feelings of frustration and hopelessness that often accompany the long waiting times at the hospitals, or other problems, when accessing mental health services.

In Study 1, in regards to LEE validation, it is worth noting that the LEE is the first self-report instrument assessing EE that has been adapted and validated in a Spanish sample of ED carers. The relative version of the LEE showed acceptable internal consistency with slightly lower coefficients than the ones reported by Cole & Kazarian (1988) using the patient version of the instrument (internal consistency was between .73 and .79 for the Spanish version of the LEE and between .84 and .89 for the original scale). In addition, consistent and quite strong relationships were observed between the LEE scale and measures of the specific caregiving experience and psychological distress, supporting the convergent validity of the instrument.

As regards the dimensionality of the scale and similarly to the results of the original version, after applying an EFA, a four-factor solution proved to best fit the data with high factor loadings and it also accounted for an acceptable percentage of variance. Notwithstanding, the Spanish version of the LEE scale was shortened to 45 items -as some of the items did not contribute sufficiently to the total scale- and used a different subscale categorization of the EE construct.

In line with findings of previous studies, the categorization of the LEE scale –both relative and patient version- has not remained stable and clear across studies, with cross-cultural studies reporting new versions of the scale with fewer items, a reassignment of some items to different scales or new subscale categorizations (Chien & Chan, 2009; Gerlsma & Hale, 1997). Since then, questions regarding the cultural validity of the EE construct have arisen. For example, Jenkins & Karno (1992) stated that the constellation of emotions, attitudes and behaviors included within the EE construct is likely to be shaped by culture, leading to cross-culturally differentiated family responses to the illness. In the present paper, for example, most of the items were removed from

the Intrusiveness subscale of the LEE suggesting that various statements related to carers' repeated attempts to establish contact or to offer unsolicited help to the patient, did not reflect dysfunctional emotional responses adopted by Spanish ED carers.

In Study 2, in regards to the FQ validation, one important contribution of this paper is that, whereas previous studies examining the factor structure of the instrument had only used Principal Component Analysis (PCA), the present study also applied CFA in exploring the FQ's factor structure. In this line, the Spanish version of the FQ proved to have a satisfactory fit with the two-factor model originally proposed by Wiedemann et al. (2002). Content validity was also acceptable although it is necessary to point out that the instrument may be improved psychometrically with the amendment of some items (i.e. Item 17: "*He/she is the most important part of my life*" –Spanish FQ- instead "*He/she is an important part of my life*" –original FQ-).

The FQ has also proved to have adequate internal consistency, somewhat higher for the CC subscale compared with the EOI, and also slightly lower than the one reported by Wiedemann et al. (2002). Thus, reliability coefficients of the Spanish version of the FQ were .83 for the CC scale and .72 for the EOI scale whereas for the original FQ they were .92 for CC and .80 for EOI. Convergent validity was also acceptable, thereby supporting the association between EE and psychological variables associated with the family caregiving. Further research in this field would be of great help in examining the predictive validity of EE in carers' well being, following the interpersonal maintenance model in EDs. Finally, concurrent validity of the FQ with the LEE scale was acceptable although it presented some problems due to the unclear factor structure of the LEE scale, as mentioned before.

Finally, another important contribution of this paper is that the FQ showed better psychometric properties and provided a better fit for the bifactor model when it was used by mothers rather than fathers. Researchers should not ignore the observed differences between mothers and fathers in their emotional response to the illness and may be encouraged to develop gender-sensitive instruments, clarifying or amending some of the already existing items from a gender perspective.

### ***3. Gender perspective in emotional response to the illness***

In Study 1, regarding gender differences in EE using the LEE scale, although findings were not reported in the published article, it was found that fathers expressed a more

Negative Attitude towards patient's illness as well as lower levels of Tolerance compared with mothers. In turn, mothers showed higher levels of Intrusiveness than fathers. Given the unclear categorization of the LEE scale, more attention will be drawn to gender differences with the "purer" two-factor structure of the FQ.

Therefore, in Study 2, one of the main conclusions was that fathers and mothers presented a differentiated emotional response to the illness, with higher levels of EOI among mothers and more CC (although not significant) among fathers. In line with findings of previous studies, overprotectiveness is a common emotional response adopted by mothers (Kyriacou et al., 2008a; Szmukler et al., 1996). This is congruent with the idea that mothers frequently have the main responsibility for providing formal or informal care for their sons/daughters (von Essen et al., 2004), and thereby become more emotionally over-involved with their child's recovery process. In turn, fathers' attitude tends to be more distant (Morris, Woods, Davies, & Morris, 1991), sometimes critical and hostile, due to their lack of understanding of the illness or perhaps due to their exclusion from research studies or treatment decisions. Similarly, Bedard et al. (2005) also highlighted gender differences in family caregiving suggesting that women may be perceived as more appropriate for the caregiving role and as a consequence may feel a greater requirement to fulfill this role.

In addition, another important contribution of Study 2 has been that the FQ, when it was completed by mothers, showed better psychometric properties compared with fathers and as a consequence, the maintenance model offered a better fit among mothers. Therefore, one can assume that the item construction of the original version of the instrument was done without following a gender-specific approach, taking into account women's typical emotional responses to the illness as carers more than the typical responses of males. Thus, the importance of considering a gender-specific approach when developing new measures assessing the experience of caregiving should be considered.

#### ***4. Further evidence for the interpersonal maintenance model in EDs***

As mentioned before, family's lives become monopolized by the illness and its symptoms. Clinical observations and research findings suggest a consistency in the way that family members respond to the illness, highlighting a number of patients' and carers' characteristics that may influence negatively illness outcome and family



caregiving, such as illness duration and ED diagnosis, among others (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). For example, in Study 1, after establishing an ED diagnosis for each patient following a categorical perspective in EDs, it was found that carers of patients with BN expressed a more negative attitude towards the illness than carers of patients with AN, in accordance with the findings of Winn et al. (2007).

However, a novel contribution of Study 3 has been that illness-related symptoms and behaviors were examined following a dimensional approach in EDs. In this way, symptoms and behaviors reflecting patient's preoccupation around food, eating and weight were studied from a transdiagnostic view as manifestations of an illness that evolves over time and does not remain locked in specific diagnostic categories (Fairburn, 2008).

Zabala, Macdonald, & Treasure (2009) in their systematic review highlighted the importance of specifying whether the impact of caregiving is specifically related to ED specific symptoms and behaviors or to what extent it is related to having a child with a psychiatric problem. Five years later, an updated review of the literature carried out by Anastasiadou, Medina-Pradas, Sepúlveda, & Treasure (2014) uncovered several advances in findings on family caregiving, identifying factors that can impact carers outcomes, such as culture, gender, and illness duration, among others. However, the absence of comparison studies made it impossible to answer the question raised above.

With this in mind, Study 3 contributed to existing knowledge by providing additional elements that can influence the specific caregiving experience among ED families, such as the presence of the ED specific symptom of purging in patients. In addition, further evidence with respect to the maintenance model in EDs has been found by showing that the presence of purging behaviors among patients affects the power of EE in predicting psychological well-being in carers in a different way than in those cases where purging behaviors are not present. More specifically, psychological distress of carers of patients with purging behaviors was better explained by their tendency to intrude on the patient's privacy, often offering unsolicited help to him/her. This kind of emotional response may be better explained taking into account the high levels of secrecy and the serious physical risks that often characterize the illness (Halmi, 2002), which may increase levels of concern in carers. In turn, distress among carers of patients without purging behaviors may be explained by their tendency to adopt a critical, often blaming, behavior toward a patient who often sees himself/herself as passive and powerless.

Finally, summarizing the key contributions of the present thesis and returning to the hypotheses posed at the beginning of this study, it is now possible to state the following: First, the Spanish versions of the LEE and the FQ have shown satisfactory psychometric properties allowing for their use in Spanish families of patients with an ED, confirming thus the hypotheses proposed for Study 1 and Study 2. Second, the hypothesis regarding the clear two-factor structure of the FQ was also confirmed after the CFA used in Study 2. Third, the gender differences observed in the emotional response of carers to the illness can be interpreted as supportive of the second hypothesis of Study 2, with mothers being more emotionally overinvolved and fathers more critical in their emotional experiences. Fourth, the evidence from Study 3 suggests the importance of identifying purging as a significant clinical marker of increased risk of psychopathological distress in ED carers, confirming thus the hypothesis posed for Study 3. Finally, further studies using different cultural backgrounds are needed in order to examine factor structure of the LEE scale cross-culturally.

### **Clinical implications: Reducing expressed emotion and distress among carers**

The findings of the present thesis have important implications for carer interventions and better treatment outcomes. A step forward in the development of new interventions might be to take into consideration the cultural issues that arose in Study 1, regarding the different categorization of EE across cultures. Although it seems clear that in previous studies more attention has been drawn to intra-familial and individual aspects of family caregiving in EDs (i.e. coping strategies, sociodemographic characteristics), the limited available research on how different cultural backgrounds may lead carers to adopt different emotional and behavioral responses to the illness, has revealed some interesting findings. For example, Hoste and colleagues (2012) in a sample of AN patients from Chicago found that white family carers expressed more warmth and positive remarks towards the patients than those carers in ethnic minority families, while few differences were found in criticism or emotional-overinvolvement. Therefore, it would be interesting for future research to take into account cultural differences between carers regarding their emotional experiences of caregiving when developing and carrying out family-based interventions.

Study 2 highlighted the importance of considering a gender-specific approach when carrying out interventions that aim to reduce EE among carers. In recent years, it has

been pointed out that, in order to improve the effectiveness and efficiency of psychological interventions for carers, we need to know more about specific characteristics of carers and their needs (Gitlin et al., 2003). Therefore, differences between fathers and mothers in their dysfunctional patterns of response to the illness should be examined in order to gain a more comprehensive picture of the risk and protective factors in the family environment. For example, the tendency towards emotional overinvolvement in mothers and distance or criticism in fathers, in their attempt to fulfill their gender role as parents, should be addressed in family-based interventions, without losing track of specific characteristics of each family.

In turn, Study 3 pointed out the importance of targeting ED significant behaviors and clinical manifestations that may affect carers' responses to the illness in different ways, when carrying out family-based interventions. In accordance with this finding, previous research has shown that helping carers to achieve a better understanding of the illness, its clinical manifestations and the comorbid behaviors that typically accompany it through psycho-educational programs, can help carers reduce their overprotection or criticism (Uehara et al., 2001). In addition, EE has proven to be an important, not static, construct in the evaluation of psycho-educational programs also among Spanish samples of carers. A recent study by Gutiérrez, Sepúlveda, Anastasiadou, & Medina-Pradas (2014) has shown interesting results concerning this topic. A new six-workshops design, based on the previous psycho-educational program which was developed by Fairburn (2008), was adapted for Spanish carers of patients with an ED showing a reduction in their emotional overinvolvement, which was maintained throughout the treatment period. The program was highly valued by the carers, who expressed high levels of satisfaction and a greater capacity to recognise and understand ED symptoms and behaviors from a transdiagnostic view of the illness.

## **Limitations**

### ***Participants and Generalizability***

First, in order to further improve the generalizability of the present findings, more care should be taken to achieve a more homogeneous sample in terms of age and illness duration of patients. Second, although the majority of the samples of carers can be considered representative and generalizable to the general population of ED carers as it was recruited from public hospitals in Spain, it should be noted that almost one third of

the participants in Study 1 and Study 3 were recruited from the ADANER association. It is therefore possible that this group of carers is not representative of all carers in the area of EDs, in that they are actively and voluntarily engaged and involved with services and support networks.

In addition, the majority of the ED diagnoses used in the three studies were established by clinical interviews provided by health professionals at the respective public hospitals, following DSM-IV-TR diagnostic criteria (American Psychiatric Association, 2002). A potential bias lies in the fact that, specifically for the ADANER sample, the diagnosis for each patient as well as a description of illness-related symptoms and behaviors (used in Study 3), was collected through a self-report survey completed by carers. Thus, a weakness regarding the reliability of carers' reports about clinical features of the disorder was added.

### *Correlation, not causation*

The cross-sectional design of the three papers does not allow us to draw unidirectional conclusions regarding the relationship between the variables studied. For example, in Study 3, it has been found that specific ED symptoms and behaviors may provoke relatives' adverse emotional responses to the illness, which in turn, may make the caregiving experience more burdensome. However, the hypothesis that unhelpful patterns of relatives' responses may fuel specific ED symptoms cannot be rejected. Without adopting a longitudinal design, causal relationships between different variables cannot be guaranteed as the associations, being correlational in nature, can be interpreted in both directions.

### *Measuring Expressed Emotion*

EE has traditionally been assessed through interviews and observer ratings, mainly using the CFI or the SCFI. Interviews have been considered the gold standard method for assessing EE, presenting various advantages compared with self-report instruments. For example, the actual home environment expressed from the verbal and non-verbal attitude of the relative during the interview may not be captured by a self-report questionnaire. Moreover, an underassessment of EE of 28% was found using clinical interviews versus self-report instruments (FMSS versus FQ) (Möller-Leimkühler, 2005).

Notwithstanding, as mentioned previously, self-report instruments present several advantages as compared to interviews, in terms of their cost-effectiveness and

clinical/research applicability. Moreover, it is worth noting that the percentage of ED carers with high levels of CC and EOI notably increases with carers' subjective perspective compared with the ratings given objectively by interviewers trained in EE (see Table 2). For example, in the study of Pepin & King (2013) using the FQ, 64.3% of carers expressed high CC and 85.7% of them expressed high EOI as compared to Sepúlveda et al. (2010) findings using the FMSS where 19.1% of carers expressed high CC and 36.2% high EOI. In addition, in Study 2 of the present thesis, 37.4% of the mothers showed high CC compared with 33% of the fathers, while 55.2% of the mothers yielded high EOI compared with 42.5% of fathers. Overall, taking into consideration the advantages and disadvantages of each assessment method, a combination of objective and subjective ratings of EE, whenever possible, is recommended for future research.

### **Direction for future research**

With the present thesis, new instruments to assess the emotional experiences of ED families have been made available for use in the Spanish population. At this moment, it is important to suggest some directions for future research:

First, regarding the methodological issues that have arisen, the test-retest reliability of the two instruments assessing EE should be assessed in future studies. In addition, their sensitivity to change should be examined with longitudinal designs. More specifically, it would be of particular interest to study the predictive power of the dimensions of EE in the improvement of caregiving experience and of patients' outcomes. Finally, the establishment of a reliable cut-off point for the LEE scale should be addressed in the future.

Second, in light of the uncertain factor structure of the LEE and the cultural issues that have arisen (different values and beliefs across cultures in regards to the emotional experience of caregiving), further validation of the instrument in culturally heterogeneous clinical samples, also using a CFA, is recommended for future research, as suggested by López et al. (2004) and Kopelowitz et al. (2002).

Third, comparative studies of different illnesses and their effects on family caregiving can enhance our understanding of the EE construct and further elucidate its specific role in predicting illness course and carers' outcomes across different conditions (Wearden et al., 2000). Although Study 3 added further evidence for the interpersonal maintenance model by including illness-related characteristics that may influence

familial emotional experiences, the lack of comparative studies of different clinical samples makes it impossible to assess whether or not the impact of caregiving is specifically related to ED-related symptoms and to what extent it is related to having a child with a psychiatric problem.

Finally, as mentioned in Chapter 4 of the Introduction section, the emotional climate at home has also received a positive connotation that has rarely been made mention of in family studies. In fact, the experience of caring for someone suffering from an ED may offer a family the opportunity to develop their personal strengths, as well as increase the feelings of closeness within the family and improve family relationships and functioning (Perkins et al., 2004). Therefore, there is a need for self-report questionnaires to capture the positive aspects of the caregiving experience as well, specifically, the positive components included in the construct of EE, such as warmth and positive remarks. In addition, future interventions should take into consideration the importance of building strengths and promoting positive emotions among carers, like warmth (Medina-Pradas et al., 2011b), following positive psychology principles (Seligman & Csikszentmihalyi, 2000).

## CONCLUSIONS

- The present thesis has compiled some of the available literature on families' experiences of caring for a loved one suffering from an ED, focusing more specifically on their emotional responses to the illness, according to the interpersonal maintenance model in EDs. There is sufficient evidence to support that EE is a key variable in predicting psychological well-being in carers and better outcomes in patients, and it has demonstrated its usefulness in measuring carers outcomes during family-based interventions
- Two self-report instruments to assess the emotional experiences of ED families – the Spanish version of the *Level of Expressed Emotion* (LEE-S) and the Spanish version of the *Family Questionnaire* (FQ-S) have been validated and made available for use among Spanish families of patients with an ED, proving to be cost-effective and with satisfactory psychometric properties. Further use of these instruments in other clinical samples is recommended in future research as well as the promotion of their use to examine the specific impact of family-based interventions.
- Fathers' dysfunctional patterns of response to the illness should also be examined in clinical research in order to gain a more comprehensive picture about gender-differentiated risk and protective factors within the family environment. In addition, the importance of considering a gender-specific approach when developing new measures assessing the emotional experience at home or when carrying out interventions that aim to reduce EE among carers, has also been highlighted.
- Further evidence in the maintenance model in EDs has been obtained, following a transdiagnostic approach of the illness, by showing that the presence of purging behaviors among patients affects the power of EE in predicting psychological well-being in carers in a different way than in the absence of purging behaviors.
- There may be transcultural differences in the emotional experiences of families in EDs that should be taken into account in future research when developing new assessment instruments or when carrying out family-based interventions.
- The measurement of the positive aspects of the emotional experience of ED carers will be an important aim of future work. In addition, strengthening the feelings of warmth or positive remarks expressed by carers by providing help to transform them into a resource for recovery, may be important for future interventions.

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